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ABSTRACT

This qualitative study used questionnaires, interviews, and observations to assess what having children with disabilities means to three families. The disabilities include severe mental retardation and seizure disorder, Down syndrome, and neurofibromatosis. Interview data were categorized into the following five areas: the children, stress/anxiety, services, personal comments, and survival strategies. Data from MAPS (McGill Action Planning System) planning sessions with the three families are also provided. Results indicate that these families of disabled children do all the things that families ordinarily do to help their children grow and develop, but they do these things more intensely and for a longer period of time. Of particular note for these families was the intensity of the illness(es) of their children and the level and intensity of family interactions with health care professionals. Each family had many interactions, as well, with several other service delivery agencies. While many professionals provided positive, appropriate, and responsive service, each family also experienced very negative non-service from some professionals. Recommendations are offered concerning attitudes, policies, and service provision. Appendices contain interview questions, interview data, questionnaires, and tables of questionnaire data. (Contains 17 references and a bibliography of 39 items.) (JDD)

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CHILD DISABILITY : A Study of Three Families

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ABSTRACT: FAMILY PERSPECTIVES OF CHILD DISABILITY

Early intervention (EI) for disabled and/or disadvantaged children has become common practice in North America over the past twenty years. In response to research findings, services to young children have increasingly moved from child-centered interventions, to interventions directed to families.

The long-term process of delivering EI services to young children has been a wedge of change for service delivery to disabled people of all ages. As a result, many professionals are attempting to understand child disability and, to a lesser extent, adult disability from the broader perspective of the disabled person's family.

This study asks the question: What does it MEAN to a family to have a disabled child? It is a qualitative study and uses qualitative methods, procedures, and analyses. Three families, each with a disabled child, took part in the study. Mothers and, to a lesser extent, fathers and siblings were interviewed and observed.

This research attempts to tell the stories of each of these families through the eyes of the mothers, who are identified as co-researchers. Data were gathered through interviews, observations, and questionnaires. Data from fathers and siblings were gathered to extend the base of information and to verify each mothers' story.

Individual MAPS planning sessions were done to obtain additional information and to support the families in their daily living and long-term planning for their disabled children.

Family histories were recorded in first interviews. "Meaning" was addressed through each mother's response to systematic open-ended questions in the first and subsequent interviews. The interviewer, while attempting to keep the interviews focused, encouraged digression and elaboration. Both were completely under the control of each mother. Interviews were transcribed and analyzed in order to identify emerging themes in the lives of these families. Planning session information and questionnaire responses were recorded and analyzed for further understanding. Transcripts of interviews and all written analyses and discussions were examined by the co-researchers for respect for confidentiality, clarity and interpretation verification.

Results of this study indicate that the families of these disabled children do all the things that families ordinarily do to help their children grow and develop; but they do these things more intensely and for a longer period of time. Of particular note for these families, was the intensity of the illness(es) of their children and the level and intensity of family interactions with health care professionals.

Each family had many interactions, as well, with several other service delivery agencies. While many professionals provided positive, appropriate, and responsive service, each family also experienced unnecessary and very negative non-service from some professionals.

This author is particularly struck by three things: the amount of time and energy these parents are compelled to direct toward obtaining services for their children; the level and quality of family adaptations and coping strategies; and the level of respect and love these families generate, maintain, and continue to express to each other.

ACKNOWLEDGEMENTS

Every research project involves the work of many people. Such is the case for this project. There are at least two important differences here, however, at least as compared to most educational research that I have studied in the last decade. Because of the need for confidentiality, the real-life contributors to this research project cannot be named; and because of the nature of the research, the mothers and families of this study contributed far more than is the ordinary contribution of study "subjects". Though nameless, I want very much to acknowledge the work of these mothers and these families, without whom this project would never have been completed. Despite their busy lives, each mother gave me about five hours of their time for interviews, and each family gave me two additional evenings of their time for a family conference and a MAPS planning session. As well, mothers checked all written transcripts, interpretations and analyses before any items became public information. Because of their major contribution, I have referred to these mothers as "co-researchers", not as "subjects". While I am writing this report and will receive "credit" for the endeavor, my role has been to be the medium through which these mothers and their families have been able to tell their stories.

In analyzing the data and in trying to understand the data, I have attempted to put myself in the situation of the mothers.
I am trying to see child disability from the families' and especially from the mothers' perspectives.

It is important to acknowledge, as well, the contribution of the friends/coworkers of two of the families, who contributed to our MAPS planning sessions. They volunteered a full evening to this project and offered many good ideas and support in the session. The third family had other children living in the home, who were of an age that they could be involved in our family discussion. These siblings deserve high praise for their contributions to our MAPS planning session for their family.

Ann Crichlow, of Saskatoon, (who can be named) transcribed all our interviews and provided me with draft copies of everything and perfect final copies. Ms. Crichlow often does word processing for me and is always a big help. In this study she also transcribed audio tapes for many hours and for many pages. As usual, her work was invaluable for me and contributed greatly to the completion of the project.

I wish to acknowledge "Betty", the secretary for the department of the university to which I was attached during my sabbatical, for her pleasant manner and ready help during all the photocopying sessions I carried out in her office.

The Department for the Education of Exceptional Children, University of Saskatchewan, and the University itself, is acknowledged for the provision of time and money for this sabbatical study. I greatly appreciate having had this sabbatical opportunity.

Lastly I wish to acknowledge the advocacy group (referred to in this report as The Society) which provided me with names of contact persons for this project. Without their help I could not have attempted this study.

Barbara Bloom

Barbara Bloom Ph.D. January, 1993

DEDICATION

This study is dedicated to all the real-life children represented by "Marianne", "Bruce", and "Shane" and to their families. It is also dedicated to all the members of the helping professions who enter into the lives of these children. For the former I hope for better times. For the latter, I hope for openness of mind and a willingness to take the information from this study to make the helping services increasingly more responsive to the needs of these children and their families.

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INTRODUCTION

Background

This research developed out of my own experience working with parents, teachers, and young children, in the area of early intervention; as well as my university teaching which focusses on educational programming for persons with mental retardation of any age. Early intervention (EI) is a mediation between the child and his/her environment designed to help children develop to their full potentials. Educational intervention intends to provide a different outcome in learners, of any age, than would have come about had there been no intervention. Parents provide interventions in the course of rearing their children. Some parents, however, need support and assistance in the mediations which they provide.

Throughout North America, EI is offered to most children who are displaying developmental delay, or who are at risk for delay, in some area of human development. Children who receive EI can usually be categorized as "disabled" or "disadvantaged". In the first instance, parents may need help in providing rich and appropriate mediations for their children because of the special needs of the children and because of the "newness" of coping with a disability for the parents. In the second instance, parents may need help in discerning how to provide rich and nourishing mediations for their children, for a variety of complex reasons.

In either case, the purpose of EI is to minimize the effects of disability and/or disadvantagement so as to help cildren develop to their full potentials.

In the early years of EI in North America, very child-oriented interventions were provided (Bronfenbrenner, 1974; Consortium, 1983; Bloom, 1986). More recently, however, EI efforts have moved toward a much more family-oriented approach (Bailey, 1987; Bailey and Simeonsson, 1988; Dunst, 1985: Dunst, Trivette and Deal, 1988). With this change, professionals in the field have come to see that they need to learn new skills in order to gather information about family needs, strengths, resources and preferences (Johnson, McGonigel,and Kaufmann, 1989). We have come to see, as well, that we require more knowledge and skills to enable us to "empower" families (Dunst, Trivette, & Deal, 1988) so that they can find resources and develop skills to meet their own and their childrens' needs. In other words, in order for members of the "helping" professions to effectively provide help to families, we need to strive to see child disability more from within the context of the child AND his/her family; and we need to develop a working style which includes family members, especially parents, as full partners in the decision-making and interventions concerning the child.

Since its inception in the mid-sixties, EI has had a healthy but subtle influence on schools. As former EI children have moved through the grades, teachers and administrators have had to meet the challenge of parents who have been involved in their childrens' development and learning, and who expect to continue to be involved. Many of these parents are articulate and assertive and expect schools to be respectful of their knowledge and their interests in the welfare of their children. The result is that the changes which professionals have to make and the skills and knowledge that we have to learn are not limited to only those professionals who work with preschool-aged children and their families. Rather, the expectations that have evolved out of EI have become the expectations of many many parents of disabled children of every age.

Few people are questioning the efficacy of EI (Consortium, 1983; Dunst, 1985; Bloom, 1986; Dunst, Snyder and Mankiken, 1988). Because of parental expectations and related professional needs, many are calling for new research and the examination of new research questions which call for qualitative research methods (Dunst, Trivette & Deal, 1988, Bloom, 1991). Qualitative studies are needed to examine some of the microfactors of service delivery in EI and service delivery to the families of all disabled children and youth. We need to know more about the quality of the life experiences of the recipients of our services IN ADDITION TO the quantifiable developmental gains or losses of disabled or disadvantaged children resulting from any given intervention. The same would hold true of the more general notion of intervention which exists in any service which helping professionals provide. It is not enough to provide a service. We must continually be conscious of the effects of our service provisions on our clients and their families and providers of care.

Problem

This research attempts to understand child exceptionality from the point of view of the family and hopes to communicate the nature and dynamics of this understanding to other professionals. The basic research question is, "What does it mean to a family to have a child with a disability?" This question was investigated, both from my interest as someone working in early intervention, and also from my interest as an individual interested in the phenomenon of child disability for all ages of offspring.

Methods and Procedures

This research examined the above question with reference to three families whose disabled children are 5, 9, and 18 years of age, respectively. While these three families likely face many similar problems, it was expected that there would be interesting differences, as well, due to the differing ages of the children and to the individual differences of each family. Qualitative research methods (Boglin and Biklin, 1982; Yin, 1984; Lincoln and Gruba, 1985; Stainback and Stainback, 1988) have been used throughout. While results cannot be generalized to all families having a child with disabilities, it is believed that this in-depth study of these families, with reference to this specific research question, will help us to better see child disability from the view of these three families; and will help us to be more sensitive to, more open to the possibility of the individual strengths and needs of all families who present themselves for help and services. This report is written in the hope of opening more possibilities for genuine understanding and empathy, on the part of helping professionals, of what all families might be facing.

1. Design of the Study

Three families, each with a disabled child, were studied through interviews, questionnaires, and observations. The mothers in each family constituted the primary sources of interview data. These women are called "co-researchers", not "informants" or "subjects", because the interview information is really their data, coming from their own experience. As well, all analyses and interpretations were checked by them. My role was to become the medium through which they would tell their stories, as each pertains to the research question. The mothers responded very favourably to this opportunity.

2. Sampling

I received the name of the first family in this study from staff at a provincial advocacy group for a given disability, located in the city where I planned to enjoy my sabbatical. Names of the second and third families came from the mother of the first family.

3. Timeline

The dates of my sabbatical were July 1 to December 30, 1991. I carried out preliminary work for this project in the sabbatical city in May and June, prior to the start of the sabbatical. I did this in order to avoid "missing" possible families, due to summer holidays. By the middle of June, three families had agreed to take part in the study. Our plans were to begin the second week of September.

Excluding the first week of my arrival and excluding Christmas week, I had 13 weeks in which to accomplish this research project, or at least get all the data gathered, transcribed, and "checked" by the co-researchers. Two more weeks were removed from my schedule for a conference and visits to two Universities in the United States. This left 11 weeks for the project:

Week 1 -Family #1: Give questionnaires to parents; first interview with co-researcher, analyze; second interview with co-researcher, analyze; "check" with co-researcher, pick up questionnaires, send tapes to be transcribed.

Week 2 -Family #1: Analyze questionnaire data, give graphs to parents; family interview and MAPS planning; "check" with co-researcher; write preliminary case study, rewrite; give case study to co-researcher.

Week 3 -Family #1 Make any revisions or necessary adjustments.

Week 4 -Family #2 same as week #1

Week 5 -Family #2 same as week #2

Week 6 -Family #2 same as week #3

-travel

-travel

Week 7 -Family #3 same as week #1, also begin editing transcripts

Week 8 -Family #3 same as week #2, also editing transcripts

Week 9 -Family #3 same as week #3, also editing transcripts

Week 10 -Complete editing and categorizing transcripts, begin writing interim report

Week 11 -Complete work with transcripts, continue writing interim report

Transcripts

Approximately five hours of interviews with each co-researcher were transcribed. Audio tapes were mailed to my home city to be transcribed. First draft transcriptions were returned to me. As I received each set of transcriptions, the following procedure was set in place:

- I edited each page, completing sentences and doing whatever was necessary to make the oral/aural communication understandable in printed form. As well, I deleted some material which was not directly relevant to the question at hand. The transcripts were then given to the appropriate co-researcher.

- Each co-researcher also edited the transcripts, to make them more clear and to remove any statements that she did not want included. When each co-researcher had completed this editing, she returned the transcripts to me.
- It should be noted that very little was removed in the above two steps. Most editing was done for the sake of clarity.
- I reread each set of transcripts and sorted statements by "themes". These themes became the basis of analysis and organization of the final report.
- edited transcripts were sent to the typist for final drafts.
- categorized statements were sent to the typist for final drafts.

Instrumentation

Three sets of instruments were used in this study. I developed a set of questions (see Appendix A) which were asked of each co-researcher during the interviews. These are open-ended questions which provided structure for the interviews. At the same time, there was considerable freedom for each co-researcher to digress and elaborate her responses according to her needs and situation.

Questionnaires from the work of Carl Dunst and his colleagues (Dunst et al, 1988) formed the basis for quantifiable information and one family discussion. (See Appendix C.)

For the MAPS Planning Session (Forest and Lusthaus, 1990) I met with each family, plus a person of their choice, who knew their disabled child well. The Sessions were carried out in accordance with guidelines from Forest and Lusthaus (1990). (See Appendix F.)

Observations

Families were observed during family sessions and co-researchers were observed during interviews. In addition, I saw these families in informal settings during the course of my sabbatical stay.

HISTORIES

Family #1

Martha and David are 37 and 46 years old, respectively, and have been married for about ten years. She is a nursing instructor at the technical school and he is a research technician at the university. This is the second marriage for both. Martha has no natural children. David has three sons, (Bruce, Doug and Michael) ages 18, 21, and 25, respectively. At the time of David's divorce, about fifteen years ago, custody of these three (then minor) children was awarded to their natural mother. The older two boys were developmentally "normal"; but the youngest son displayed, from infancy, indications of developmental delay and neurological damage. When Bruce was four years old, he was placed in a residential institution in Capital City by his natural mother. Shortly after David became aware that Bruce had been placed in the institution as a resident (as opposed to a day student) he discussed with his lawyer the possibility of gaining legal custody of Bruce, for he wanted to provide a home for Bruce. At that time, he was told, in order to gain custody of Bruce, he likely would have to prove that Bruce's natural mother was an "unfit mother". He did not press for custody at that time.

Interestingly, Martha was one of Bruce's caregivers in the residential institution. David visited Bruce regularly, and eventually met Martha. Over time, the encounter became a social relationship which eventuated in marriage.

At about the time of their marriage, David again visited his lawyer, this time he was told that his change of circumstances (his marriage) probably would make it more likely that he could gain custody of Bruce. He began legal proceedings to achieve this. After a legal struggle of about two years duration, the custody litigation was settled out of court and resulted in Bruce's living with David and Martha. This occurred when Bruce was about eleven years old. Bruce is now 18 years old and attends a special class in a regular high school. Bruce would probably be labeled as functioning in the severely mentally retarded range. Last year was Bruce's first year in senior high school. It was not a happy year. A large part of the unhappiness resulted from Bruce's being terribly ill as a result of his seizure disorder(s). Gaining control over his seizures required two hospitalizations, one of which was for six weeks duration at JB Children's Hospital in Regional Centre. The remaining unhappiness at school seems to result from a conflict between what Martha and David want from the school (based on Bruce's previous experience in junior high school) and the teacher's and/or school's inability (for whatever reasons) to provide this kind of program. From an educational point of view, Bruce is probably the lowest functioning student in his special education class.

Bruce is a tall, handsome young man, with several challenging learning problems. Bruce drools quite a bit; but is learning to be aware of this and is learning to initiate a swallowing action. He has had one surgery for this problem, which has helped. Martha and David are contemplating further surgery which likely would stop the drooling altogether; but they are trying to get more information about the specific surgical procedure and its long-term implications for Bruce. Bruce is nonverbal; but understands the language of daily living, quite well. He is cheerful, inquisitive, very active (purposefully active) and agreeable. He walks with a wide base and sometimes bumps into things or loses his balance. He has a wheelchair for temporary use, if needed. He needs help on the stairs, and a chair lift has been installed in his home for this purpose.

Bruce is not toilet trained, as yet; but he can manage all the procedures of accomplishing this task. What he has not been able to do is to indicate his needs or to understand from his own body signals, when it is that he needs to use the toilet.

While the past year's schooling has not been a happy one, in the eyes of Bruce's parents, Bruce has had many happy and successful experiences of school. Martha points to Bruce's junior high school years, where he was "mainstreamed" for about 50% of his day; and to his very successful summer programs for the last two summers.

Martha also indicates how valuable it has been for Bruce (and subsequently for her and David) to have friends his own age.

This has resulted from the development of a "Circle of Friends" for Bruce, initiated by a friend and co-worker of Martha's, while Bruce was in junior high school. Trying to maintain contact with these very important friends, now that they are all in high school, and the inability of the high school to provide this opportunity, is part of the conflict of the current school situation.

While Bruce is struggling to grow and develop in spite of several medical problems and in spite of his learning and communication disabilities, he also has many talents and strengths. He is actively involved in his environment and interested in learning about it. He is a loving and appreciative human being who responds positively to loving caregivers. He is happy and energetic. He knows how to get what he wants, though he is dependent on caregivers and teachers to "read" his communications. He has real and distinct likes and dislikes. He shows his likes through enthusiasm and his dislikes through disinterest. He loves people and demonstrates his enthusiasm for people who like him; but he can be hurt by thoughtless people and internalizes such experiences. At such times, he becomes withdrawn. He is not aggressive or abusive. He loves music and has a sense of humour. He loves to tease; but likes to please, as well. He can learn quickly, as evidenced by his computer work the past summer, and he is willing to take risks. He has many "normal" traits; but these have to be "read" by caregivers and teachers.

Perhaps more so than most disabled persons, Bruce's talents and abilities are dependent on the eyes of the beholder. Certainly Bruce cannot, as yet, communicate what he is thinking or what he wants or needs in a straightforward manner. He depends on others to "read" his behaviours. This puts Bruce at risk for being misunderstood, underchallenged, and overlooked.

Family #2

Anne and Sam are 38 and 42 years old and have been married for 15 years. Anne has worked part-time as a laboratory technician. At the time of this research she is temporarily unemployed. Sam is the Chief of the fire department in a small municipality. They have three children: Marianne, age 9; Terrance, age ten; and Wayne, age 13. Marianne has Down syndrome and attends a regular classroom in her neighborhood school. She is in grade two. Her brothers are developing normally and are in grades 5 and 7.

Marianne's condition was identified shortly after her birth. At that time there was very little positive information given to Anne and Sam. The people in the hospital environment were pretty gloomy about Down syndrome knew little about it or avoided the situation. No one came from outside the hospital to provide information or support. The one exception in the hospital was Marianne's pediatrician. He provided Anne and Sam with comfort and good information, and lay the groundwork for their treating Marianne, as much as possible, like any other child.

Like many children with Down syndrome, Marianne has had additional medical problems. She was born with a heart defect, and two dislocated hips. She suffered a great deal, in her early years, from respiratory problems, including many occasions of acute respiratory distress. She has both hearing and vision problems. During her infancy, the dislocated hips required bracing and Marianne required physical therapy, including daily therapy administered by her mother. She walked at 42 months. At the age of five, Marianne underwent open heart surgery. She has recovered well from this surgery and has enjoyed considerably better health, since it took place.

Marianne has not acquired much useful speech, as yet. She communicates with a combination of speech and signing and is becoming competent in reading and writing skills. She understands what is said to her and can read primary-level schoolwork. Because of her difficulties in acquiring speech, she has had, and continues to have contact with a speech therapist. She has had two speech therapists. The first provided intervention with disastrous effects on the family. The second therapist has been much more effective in working with this family and with Marianne.

Marianne is now nine years old. She attends grade two at her neighborhood school. She enjoys school and takes part in everything. When she is not in school, she enjoys skating, watching her brothers' hockey games, shooting baskets with them, swimming, art classes, and playing with neighborhood friends. She has friends both at school and in the neighborhood.

Marianne is a friendly little girl, who likes to be with people and likes to develop her skills and interact with the world. Sometimes she can be very stubborn. The family feels that they are moderately successful in dealing with these stubborn moods.

All family members are interested in Marianne's development and progress. Her brothers are particularly helpful in keeping an eye out for Marianne at school, and in welcoming her to join their activities around the neighborhood. Marianne, in turn, enjoys being with her brothers and learns a lot from them.

In the future, Anne and Sam would like to see Marianne continue to attend her neighborhood school, taking part in as much as possible. They would like to see Marianne receive communion at church, especially to make her First Communion. As well, they would like to see Marianne's world broadened with more activities that she could do, independent of their initiation and supervision and independent from her brothers. They intend to look into the possibility of Marianne's joining a Brownie troop in the near future.

Marianne's family believes her most serious disability is her marked delay in acquiring speech. They look to the future quite hopefully, with the thought of providing Marianne with some kind of augmentive communication device.

Family #3

Sara and Phillip were married about six years ago. She is a recreation director for a program serving handicapped adults and he works is a furnace installation worker. They are 31 and 29 years old, respectively, and are the parents of five year old twins, Margaret and Shane. The twins were born in July of 1986. Shane was born with a mild heart defect. In December of 1986, when the twins were about five months old, it was determined that Shane was having seizures. Investigation at the JB Children's Hospital in Regional Centre indicated that something more complex than "infantile spasms" was happening with Shane.

From December to April, Sara and Phillip adjusted medications and coped with seizures. In April, Shane was taken, again, to the JB Children's Hospital and was diagnosed with neurofibromatosis, a condition that has left him developmentally delayed. Margaret is developing normally.

At the time of diagnosis, the neurologist wanted to try ACTH treatment for Shane. Sara and Phillip agreed to this. Sara describes the two month period when Shane was on ACTH as a "nightmare"; but she believes that it has helped to control his seizures. Later, Shane had a second treatment with ACTH for six weeks duration. That treatment was somewhat less difficult.

There were other occasions when Sara and Phillip were required to experiment with various other drugs for Shane and experiment with various dosages of drugs. At one time Shane was taking deprocaine for a period of about nine months; but Phillip felt that Shane was "intoxicated" by the drug. He pointed to pictures of Shane in the family album which showed a bright-eyed and alert infant before deprocaine, and a dull-eyed and passive child while he was taking deprocaine. They agreed on this evaluation and asked the neurologist at the JB Children's Hospital for a change of medication. He agreed with their evaluation and prescribed something else. Eventually, the right combination of drugs was found and Shane's seizures have been well controlled since then.

Both children attend day care, where Shane receives special developmental intervention for his learning needs. Sara is pleased with Shane's progress and is especially impressed with his special needs teacher, who is also the mother of a non-verbal child. She uses some signed English when working with Shane.

Shane has some behaviour problems, probably resulting from frustration related to his delay in communication skills. While he understands most of the language of daily living which is expressed to him, his own expressive language is limited to five or six words. Sometimes he cannot express his own needs.

Despite his history of seizures, Shane is very adept in large motor skills and has unusually good balance.

In addition to early intervention at day care, Shane has had two different speech therapists. The second therapist has been more successful at "reading" Shane's non-verbal communications than the first had been. This pleases Sara. In addition, Sara has taken a course in the Hanen Early Language Method, which she has found very helpful and Shane has had help from a psychologist (and his caregivers) for modifying his behaviour.

Margaret has been quite protective of Shane up to now. Recently she has grown in her ability to let Shane's special needs teacher look after Shane at school. She continues to help other caregivers with Shane by explaining to them what Shane is doing and how they should handle it (based on Mommy's model). She often communicates for Shane at home and at day care. She seems, however, satisfied to let others take responsibility for Shane most of the time at day care, now. Sara is hopeful that when they enter the neighborhood school (next September) Margaret will allow herself to be placed in a room different from Shane's. The parents make a special effort to see that BOTH their twins receive appropriate attention and direction.

Sara says that Phillip is very good with both children and has been especially successful at establishing an early bonding with Shane. Both children love their father dearly and look forward to time spent with him. Because Phillip has been off work or has had part-time jobs, now and again, he often has charge of running the household and of looking after the children.

INTERVIEW DATA

Introduction

The co-researchers of this study, Martha, Anne and Sara, were interviewed, individually, on two occasions. These yielded approximately five hours of interview data from each co-researcher. All questions were "open-ended" and mothers were free to diverge and to discuss any matter which interested them. In general, the first of each mother's interview was planned around the general statement, "Tell me what I need to know." The second interview delved more deeply into items presented in the first interview and into the personal factors associated with parenting a disabled child.

Interviews were transcribed by an assistant. Co-researchers checked all transcriptions in order to clarify specific statements and to eliminate any statements that each might wish to keep private. Only a few statements were removed.

Following checking and editing by each co-researcher, transcriptions were analyzed by this author to categorize the interview data into the themes which emerged from each mother's story. The five major themes are as follows:

The Children
Stress/Anxiety
Services
Personal Comments
Survival Strategies

Categorized data can be found in Appendix B. Sub-headings emerged within each theme. Most sub-headings contain comments from every mother, indicating that these three mothers had very similar problems, concerns and satisfactions. The themes of their lives as mothers in families where one child has some disabilities are quite similar.

Oral language is quite different from written language. Nevertheless, I have presented the co-researcher's statements in written form exactly as they were stated. For clarity, I have made sure that first pronouns referring to the children have been changed to proper names and have occasionally added phrases of clarification which are set off in parentheses.

Upon reading the interview statements, the reader will begin to see the complexity of the situation of parenting a child with some kind of disability. Many statements could be placed in several different categories. I have tried to categorize these statements in a manner that is faithful to what I saw to be the total perspective of each mother's experience as she communicated her experience to me. Most interesting findings from the categorized data are presented here.

The Children

1. Descriptions

Bruce, Marianne, and Shane display inquisitive and active personalities. Each likes to laugh and play and each has individual patterns of play and learning. These children are able to learn; but those who interact with them need to make accommodations which take into account each child's individual learning needs and personality traits. Communication is a big problem for all of the children. Each family has searched for and continue to search for ways of making communication more available to their children. Each child shows competencies and skills and interesting personality traits.

Quotes # 1

He (Bruce) wants to please. He wants to know he's done well. He looks to be told he's done well. I think a lot of people don't even recognize that he's looking for your approval, when he's made something happen. A: He recognizes he just did something right. And B: he's looking for you to recognize it. And if you can't see that that's what he's doing, you don't recognize it. It's a lost opportunity right away... It's gone. And it's so sad because it's so critical for Bruce.

Because I look at Marianne and the little that she could communicate to you that you'd be able to understand, but yet I often wonder how extremely smart she is. She's at a double, double disadvantage in that. If she had the speech, she'd really be spinning their heads down there at school. She'd be just spinning them... Because even though her communication is poor, she lets them know that she knows what they are teaching in the classroom and... "Don't count me out!"

A lot of Shane's behaviours are autistic... autistic-like behaviours in a child with tubersclerosis... Sometimes he'll be off in a stare. I just tell him that he's going to be o.k. and say, "Now, just relax".

I recall a story of the grade one teacher, the first couple of days that Marianne first went to school. Well, she gave all the other children numbers to print on a sheet. I believe it was the number 4. And when she came to Marianne's desk, she gave Marianne a nice picture to color, because she wanted Marianne to have success. Her intention was honourable. I'm not saying anything about that. She thought Marianne could color but she couldn't do numbers. O.K. this was a low expectation. So Marianne looked to the left of her and she looked to the right of her and she saw both students with the number 4. So she took up her colouring page to the teacher. She put it down on the teacher's desk and she said, "Four, please." She wanted the number 4. So the teacher.. and she'll tell the story herself, was so astounded that Marianne knew the number 4 that she couldn't find the 4's page fast enough. She was astounded! And she said from that day forth, whatever the other children were getting in the classroom, Marianne got too.

I know that Bruce is severely mentally handicapped and I don't think either one of us has tried to deny that, but I think that his inability or our inability to figure out a way to get him to communicate has really held Bruce back a lot. You always get the sense from him, once you get to know him, that there is a whole lot going on in there that just isn't coming out... Because we have not found a way to help him get it out.

If you're accepting of Shane and you take the time to show him that communicating and language is important. When he's vocalizing, I try to turn it into a word and I communicate back to him, to show him that talking is fun... That we both need to talk back and forth.

Bruce has a really good memory. He knows things. David is a bag-piper so whenever the bag-pipe comes out, Bruce is doing heavy breathing. He's all over his dad and he knows. He's trying to get the case open and he just knows that the pipes are going to be played. He is crazy about them.

Marianne would walk home anytime from school. I think maybe it is my own fears that keep her back. I have to put a lot of blame on myself. I'm not confident enough that she has the skills to walk up that road by herself... I worry about cars and other things she tends to do. For example, if she has a rock in her shoe, she sits down in the middle of the road to take the rock out of her shoe.

Shane wasn't coming up and making the connections with me. Telling me "I want you". Or coming up and sitting on my knee or doing all that kind of stuff. It's just been ever since I took the cars... And I had to do funny things. He'd run around the room from one end to the other and I had to run around the room behind him and if he put a toy into his mouth, I'd put a toy into my mouth... And I did this for a while just to get into his kind of world. It was so funny. I'll never forget one day he took a car and then put the car in his mouth. I went and took another car and put the car in my mouth. He turned around and he looked around and all of a sudden he realized that I was imitating him. And he started to laugh. Ever since then it's been great. We just have a natural way of communicating and that just makes all the difference.

Marianne loves to dry the dishes and things like that... make the beds and fold the clothes and she's the neatest child I have. She always picks up what she lays out, always puts it away. She's the neatest. She hangs up her coat and things like that. She likes exercise. She doesn't very often sit.

Shane has to be praised... This is probably one characteristic on the negative side. You just can't say you did a great job Shane. You have to go "Oh! Boy! I really like what you did, Shane. Boy you're a really smart little fella", and then it's the big smile on the face. So you have to go overboard in order to get a reaction from Shane. That's why a lot of people find it hard to work with him. They aren't used to him, because you have to really give of yourself to get the reaction. But it does come.

Bruce is the kind of kid... If he is not happy and something is wrong he is not the kind to lash out or hit anybody or hurt anybody or bash his head or do anything weird like that. He internalizes everything and he just shuts down, basically, so that when things aren't satisfying to him and he is not happy he just shuts his eyes and falls asleep. He doesn't really fall asleep because he walks around the school with his eyes closed. You can't be sleeping and walking around with your eyes closed but that is his behaviour. That is how he copes. He just shuts down. It's the one thing he has control over.

2. Friends and Social Learning

Friends are important to Bruce, Marianne and Shane and they have had varying experiences of success in establishing friendships. Like all parents, friendships for their children is important for Martha, Anne and Sara. Each family spends considerable energy in providing opportunities for friendship for their children. Siblings have been an important link for Marianne and Shane in helping them to be involved with other children and in giving them the opportunity to be exposed to neighbourhood play and school or day care experiences. Siblings have also helped to mediate the environment for Marianne and Shane. The "Circle of Friends" (Perske, 1988) has been a good support and learning opportunity for Bruce. In some ways, Bruce's "Circle of Friends" plays a role in his life which is similar to that which is played by the siblings of Marianne and Shane.

Quotes #2

When I look at Bruce before he had friends in his life and just take a quick snapshot of what his life was like before... it was not a pretty picture. His whole life revolved around David and I. He also just wasn't the same person that he is today. He wasn't as assertive. It (having friends) just turned everything around. It's difficult to talk about it now. I used to be able to talk about it because it was so fresh. Life without friends was all we ever knew. That's really distant for us, at this point. He never went anywhere unless he went with us. You know, the focus of his social life was a trip to the K-Mart on Saturday mornings. And I'm serious about that. He never went anywhere.

There's a group of children Marianne plays with at recess and lunch time. She's not a loner. She's not just in a corner somewhere playing. She's in a group when she's playing. Terrance quite often goes over at recess or something and shoots a few baskets with her or something like that.

They'll talk to Shane even though he doesn't speak back to them... They will talk to Shane and Margaret and get things for him or do things with him.

Well the Circle of Friends just took off. By the end of grade 8 school year, Bruce had 12 or 15 kids who just rallied around him. And they started putting pressures (in their own very special way) on the system about: If he's in home-room why isn't he in this class? And why isn't he in that class? He ended up getting about half of his time into regular grade nine, junior high level. That these kids could really be friends with someone like Bruce! They really have that capacity to truly care. That is not some pity thing or volunteer work that they choose to do for a year and then let it go. Their relationship with Bruce is based on the fact that he's a person that they care about just like it would be for anybody else. (Understanding) that took some time for us. It took some time.

If I put on some music, sometimes Shane'll.. Margaret will be dancing around there, Margaret wants to dance with me and I'll go and dance with Shane and Margaret. I'll have one on one side and one on the other. We'll be dancing around the living room.

Marianne imitates those two boys (her brothers) an awful lot... An awful lot. In their actions and in their movements. She models their actions. For example, if they score a goal in hockey, or their wind-up when pitching a ball, or doing their homework, and things like that.

One example of embarrassing incidents was last year. It was at lunch time. There were some kids around the grade one doors and I believe they were older kids in other grades. They were encouraging Marianne that perhaps she should take her shirt off... and then I think they perhaps were going to go further than that too, with all the clothes cause they told her it was a hot day, that she should take her shirt off, which she did. She took the shirt off. Well, I think there was a couple of buddies of Terrance who came and got him on the school ground, to come to her assistance. And he came directly over and got the shirt back on her and told her not to do that. Well, a teacher happened to be on duty as well, and saw what was happening. But Terrance did the handling of the situation... He (Terrance) didn't want to disown her, which is what I got out of the situation, anyway. He didn't want to disown her, although he was embarrassed by it. There was no doubt about it. But he wanted to get to the one who really caused the problem...

And then the older brother (Wayne) last year was in grade six. It wasn't that dramatic of an incident, I don't think, but uh... Marianne was in the corridor and she was running away from the teacher assistant or something. She was in one of her little moods there. She didn't want this teacher assistant and I guess she was making quite a bit of noise out in the corridor. She happened to be going by Wayne's room in school, and somebody in the school said, "Oh, there goes your sister." So Wayne went out and he calmed her down. He handled it. He did that on his own accord. He will check in on her for a few minutes at recess and noon break just to see that she is happy doing something.

With Margaret, she is really good with Shane's disability, cause she'll let people know what's going on. She knows when he's taking seizures. She'll tell people that don't know... She says, "Shane is taking a seizure and Mommy usually just says, 'It's o.k. Shane. You're going to be all right, you're just taking a seizure'".

I don't know how she communicates with Shane but it's.. She'll just say Shane wants a drink or things like that... just, out of the blue... He doesn't have to be standing by the sink or anything like that for her to know what he wants. He'll use vocalization to request a need. Usually crying or going to the cupboard etc. She can just... sometimes I can't figure out why he's upset or something and she'll just have the answer, and I say to myself, "Boy, why didn't I think of that"?

You don't make friends and maintain friendships with people that you don't see in school on a regular basis. That is the part that we struggle with the most in trying to get the school to see that they have a role to play (in maintaining Bruce's 'Circle of Friends')... If Bruce lost all of his friends today we would simply be impelled to go out and start again. Because we couldn't deprive him of all the wonderful things that have ended up happening.

Parental Stress/Anxiety

1. Children's Development

Like parents everywhere, the parents of Bruce, Marianne and Shane have many stressors in their lives. For the parents of these disabled children, however, the "normal" stressors seem to last longer and seem to take on a greater intensity. As well, there are additional stressors which arise from each child's disabilities.

Quotes #3

Any time Bruce cries .. he cried yesterday for the first time in months because he was hungry... He cries for reasons. He never just cries for anything that we can't figure out why. Well, we were late in getting supper and Bruce was sitting and all of a sudden he started to cry and we said "Bruce, are you hungry?" and he went (smack, smack, smack).

Even as Marianne gets older, we wonder will she ever be able to be left alone for a short time?... But with her communication problem, I don't think I would be comfortable enough to ever do that. I can't see babysitting ever ending.

Shane was hitting and slapping and screaming and things like that... He's frustrated. He's very frustrated. He doesn't have the language to be able to express what he wants to say. And he will become quite frustrated.

Oh my goodness, we had a hospital crib with big high sides, and I kept Shane in that for the longest time. One morning I went in and here he was just sitting on the edge of the crib, just balancing. I mean it was only about that wide. Sitting there. Another time I went in and I found him walking. What was he walking on? The rail along.. He had climbed up onto the dressers, got into his crib and was walking along the railing of the crib. I just couldn't believe it. Then we have a ledge downstairs in the basement that's four feet up, and he walks on it. He walks on it all the time. I'm forever going down and finding him up there.

A lot of games we started playing around, you know, just sort of functional cause and effect things have made things a bit crazy around the house. Bruce is constantly turning the dishwasher on and he is, you know, switching on and off the lights on us and all this stuff and running to flush the toilet and turning on taps. But it's neat stuff so I guess it is nice to be busy in that way with him versus some other way that is maybe less productive for him.

There are reasons to doubt. You know, we're worried about all our children walking home from school and everything like that. But your other children can handle the situations that might come up on that road home, whereas I don't know if Marianne could handle some of this on her own and her brothers aren't always going to be there... There has to come a time, definitely.

I guess one of the big things, is if Bruce could communicate, could he tell us things like, " I'm uncomfortable and I need to go to the bathroom"; would, all of a sudden, toilet training not be such a big issue for us anymore? Or even the visits... Bruce's friends are about as good at "reading" Bruce as we are... But if they come by, you can't read "What did you do yesterday Bruce?" And he can't initiate any contacts with them.

2. Illness/Disability

Specific illnesses in their children, which have been more serious than the usual childhood illnesses; and, especially for Bruce and Shane, will continue indefinitely, bring serious stressors into the lives of these parents.

Quotes #4

Anyway, Bruce was just so sick and he spent about 3 weeks in Regional Centre and I kinda lived... I didn't live in but I stayed in Regional Centre. I couldn't live in I just couldn't handle it. I was there from 9 in the morning until about 9 at night and then I left and had time to myself in the evening.

Nobody would come near Marianne when she was an infant because (When I look back on it now and thought, at that time, that it was valid) they were very scared to look after her because of all her health problems. Because you could lay her down at eight o'clock and then at ten after eight she could be in real distress breathing. And indeed, that was a valid point. But I wonder if they didn't play on that too? Thinking that, all right that's a legitimate excuse and, you know, they're going to say they don't want to look after her because they're scared that something was going to happen to her.

We went back again for the second time. It was then Shane was diagnosed. They wanted to try a treatment called, A.C.T.H.. It's a steroid. And I had to give him needles. I was petrified of needles... Well, they wanted to teach me how to give the needles. I thought, "Oh, O.K. if I'm going to have to do this, then I'm going to have to do it". So I learned how to give him these needles and it was just.. There was a period there for about two months that it was just a nightmare.

If we (Martha and David) didn't have to worry about seizures, life would be wonderful. And people think I'm crazy when I say that but life is such hell when his seizures are out of control.

You know, there were plenty of mornings that I'd be doing the physio or something and the neighbour would come in and leave because she couldn't stand it... seeing me do this... trying to get those legs straightened up. I'd have Marianne plastered up against a wall, and she was just screaming her bloody head off... And all that the neighbours could think was, this was too cruel. They can't witness that. So they were free to go out the door... I didn't want to have her crying either... But I wasn't free to go... I had to put up with that. I couldn't go out the front door and shut the door and be gone.

Marianne was so sick and ah, I just... I didn't have anything... I didn't have anything else in my life other than her physio in the morning... An outing for me was to the clinic or to the hospital for an x-ray.

I always felt there was something holding me back from totally loving Shane the way he should be loved... It was like, I don't know. We couldn't make that communication. There just didn't seem like... Him and his father seemed to be quite good, you know. They bonded together quite good. But we couldn't seem to make that connection. I'd hold him and everything... I had a real problem with that because I felt something was holding me back... I think it was the fear that something was going to happen to him, that he was going to die. I didn't know what I was going to do.

3. Illness/Disability/Financial

From time to time, these parents feel financial stress because of the special needs of Bruce, Marianne and Shane.

Quotes #5

We get ours (diapers) from another province because they are cheaper. We have them shipped by courier every month. It works out cheaper to do it that way. But anyway, I mean that the money for Bruce just doesn't go very far. But if he was in a room and board situation or in a group home or living in foster care somewhere, there would be a lot more public money put into his keep. And it's not like we want to get paid to look after him. But there seems to be some kind of injustice here, in that we are just here twenty four hours a day for Bruce, basically free of charge to anybody. And somehow, at some point, you think this isn't right. Bruce is eighteen years old and if he didn't have a disability and he chose to live at home, it would probably cost him.

We took Shane down to Dr. Kelly and um Dr. Kelly said that he was taking infantile spasms... And that it was an emergency. He had to be taken over to the hospital in Regional Centre right away. It was just all of a sudden. It was Dec. 5th, I think. And he was only five months old and we went over to Regional Centre... I found it very frustrating at that time, too, because it was just around Christmas time. Financially we didn't have the money to go. Everybody that time of year has done Christmas shopping. I had done my Christmas shopping and I just didn't have the funds available to me to go to Regional Centre... Anyway I was lucky in that an aunt lent me the money to go to Regional Centre. I had to stay over there for a week.

They (sitters) are not in plentiful supply. There are some girls that I can get that are very reliable. But it's costing double because you pay a good amount of money for somebody that you know, will do it, and is reliable.

I have done the fighting to get Shane early intervention because both me and Phillip were not working at the time. I fought for nine months to get Shane's day care costs covered because we were both not working and weren't requiring day care, we were requiring early intervention...

If I were a foster parent, I wouldn't have to worry about going out working trying to make some money. They'd provide me with everything. I'd get so much respite care and I'd get money for looking after the child and everything. But if we ask them for anything for our own natural child that we try to keep home, it's a fight... The phone bills to Regional Centre (when Bruce was sick, for example) were just atrocious, $200 to $300 a month just to phone to Regional Centre.

4. Illness/Disability/Parental Work

Martha, Anne and Sara have ambivalent feelings about working outside of the home which are intensified by their children's disabilities.

Quotes #6

Well, to be perfectly honest, it really would have been nice to have somebody come to me from my employment to say, "It's o.k.. We know that right now Bruce is more important than anything. I never got that once... So I always walked around feeling guilty, and trying to justify x amount of time spent at work and x amount of time spent with Bruce. I would raise the subject every once in a while about that and it would be... it would not be as understanding as I hoped that it might have been. Um, it was more..." Well, when do you think he's going to be better? When do you think you're going to be back?..." It just would have been helpful to think I didn't have to worry about the work situation so much. Cause that really stressed me out..

It was that second year that Marianne was in day care that I went back to work part-time. I worked the mornings. Well I worked as a lab technician at the Capital City Clinic but we just got laid off there the other day... The Clinic closed. So I did that in the mornings, which was great for me too. I had to get back out in contact with the adult world. I just had too. I just had to make that contact again, because it was too much at home. It was hard enough when you had young ones at home. Everybody realizes that, but when you have all this extra stuff that you have to do for one child.

I (Sara) can get depressed if I'm home twenty four hours a day, seven days a week, that kind of thing. You can just get too depressed. I need that contact with the outside world. But I sometimes feel that I'm cutting myself up into too many chunks and not giving enough to everybody..

Well, I don't know if I (Anne) want to explore more education for myself. But there are times that I wish that perhaps I was a person that could be employed full time outside the home. I really feel, even up the this point, that I'm not marketable to be full time, because there's no employer that would give me the amount of time off required to attend to Marianne's appointments, that can only be done on a nine to five basis.

I (Sara) find it very difficult right now to be working and to do all the things that I feel that I have to do. There's just not enough time. There's not enough time for me. I'd much prefer if I only had to work three days a week. Because I'm finding that... It's just that sometimes I have to work because I need that. I need that connection with the outside world.

But there was a lot of pressure that I was feeling from other workers to have some answers about when Bruce was going to get better. All I wanted to do was get through a day.

5. Isolation

Feelings of abandonment and isolation are expressed by these mothers. While all three are experiencing good support from their husbands, and all three have intimate friends outside of their immediate family circle, only Sara has found consistent support for herself and her problems outside her home. There are special reasons why this is so, and why she needs more intense support from friends than do Martha or Anne. This will become clear from Sara's statements in this section and the next. For the most part, two of these three mothers carry on their lives with little support and encouragement from people, apart from the people with whom each lives; the third mother has found the extra support that she needs and uses that support in ways that help all the members of her family.

Quotes #7

Boy, I think if it wasn't for just having somebody like David, you know, where the two of us... we experience the same kinds of feelings. We have the same kinds of hopes and anxieties, or we seem to. I think we really help one another.

The doctor that was attending me (Anne) at the time, the obstetrician, had no idea in the wide world on how to cope with the situation. So he ran from it, to the point that I was five days in hospital and I didn't see him over the space of five days. He never came back. That was the end of him. He was gone.

They (grandparents) were shocked that this (Down syndrome) happened and offered support by saying, "Oh well, you can handle this." "Things won't be that bad." This was both sets of grandparents and that's on-going. That's an on-going thing right to this day... I don't think it's rejection. I think it's more a fear of what to do or how to act or... What would I do in a situation if she happened to take a stubborn streak or something like that? I think it's ah... No I can't say they reject her. Both sets of grandparents, I think, are very fond of her, but at a distance. As long as we are there you know, to be the main care-givers and look after her. They imply, "But don't expect us to jump in and try to alleviate some of the stress." No we never did have that kind of hands on support. And that holds true to all extended family members. I can honestly say that there's no support in that family unit.

And another good thing, when it's a couple doing it. I mean don't get me wrong, there's times when I'm burnt out wanting to wash my hands clean of it all... But when if you have that extra strength coming from the other side that wasn't so involved in it. A strength that could then take over, so you get rejuvenated again in order to carry on with the task that needs to be done.

To be honest we (Martha and David) have a bit of resentment when we hear one sister saying to the other, "Well I'll take your kids this weekend, if you'll take mine next", and all this. I know that Bruce is not easy to look after and people would have struggles with that but there's a lot of things that Bruce likes to do like just go for a drive in the car. I keep thinking that it wouldn't kill them, if they're out for a drive, to come and pick Bruce up and put him in the back seat, put his seat belt on, take him for a drive. He's not going to hurt anything or touch anything or...

Ya, it's lonely though, if you're the only one in a big school like that. We have an enrolment of 550 down here. It's lonely. If you had another family that had a child that is trying to be integrated into the system.. it would be better.

The pressure is on us, his parents to always be the ones to make sure that Bruce sees his friends after school, evenings, that sort of thing.

I just forget to say, "Well what do you think? or "would you like to come?" (to Philip). I never thought to turn around and say, "Would you like to come with me to this?" Or" Maybe we'll do it when we both can do it." Or "Lets set up a time." I guess I've just kind of gone out and done the things that had to be done myself. I find that happens an awful lot.. You get an appointment and you say, well I'd better take it because it might be months before that person's going to make it back here again. You can't just go anytime when you want to, or when it's convenient for you. It's always convenient for them (the professionals).

I wish that I (Sara) had started right from the first. I wish that there was some way that they could speak to you, somebody in the support program or something that would say, "Can your husband become more involved? How can we keep this a family thing?" Because sometimes you just get so desperate in your struggles that you forget that you've got a family unit that can work together to get things accomplished. And use each other and lean on each other and that kind of thing.

He (Sam) can step in quite easily when he takes her for a little while. "All right, Marianne, we're going for a little drive." or "Let's go down to my office and play with my computer." And it always seems to be at the very best time where I say "Oh my Lord. You know she and I have to be separated for a few minutes here..." So it always works out well there, too. And the boys seem to pick that up, as well.

Well I guess when I look back, it (Martha's inner strength) must be pretty good to go through... I mean sickness and the... And I'd have to say it's pretty darn good because there hasn't been a whole lot of support anywhere else other than in our immediate family so...

It's the five of us (Anne, Sara, Terrance, Wayne, Marianne). There's not another person that comes to mind that I'd jump in and say, "Well, they really helped us out in the bad times."

It's hard to extend the hand and ask for help. If I would have involved him (Phillip) right from the start, but you see, I didn't realize...

I worry if something gets in the way of my being able to keep it all together. Because, as I said to you last night, sometimes it's like David and I are against everybody. And there's just the three of us (Martha, David, Bruce).

6. Additional Stress

Sara is parenting children in a family with some special needs in addition to those which arise from the disabilities of one of her children. She has found support for these special needs in already existing services to assist people to cope with the daily living stresses of alcohol abuse and/or eating disorders. Sara has learned how to find these services and thus to find support for herself and her family outside of the family. Moreover, she generalizes the principles she has learned from these already existing support groups to the problem-solving she must face concerning Shane's special needs.

Quotes #8

Oh back three years ago it was extremely stressful. I lost all self esteem. Oh, not all, I must of had a little bit of self esteem to get me into Al-Anon...

I was just like everybody else that lives with the disease of alcoholism. It just affects the family in that way. The wife becomes wanting to control the situation. She feels that she should do something because this person is out of control. They're spending money that they don't have to spend. They're becoming aggressive when you go out to dances and things like that. You can't enjoy yourself. You feel that people are.. that people are holding you responsible. And a lot of people will hold you responsible...

I realized that this person was a sick person. He wasn't just doing it to be mean to me or that he didn't love me. I know that Phillip wishes for anything in the world to be able to be normal, to be able to drink like everybody else, because he see's all his other friends going out and doing it. And he say's why can't I? And he doesn't understand... I understand the fact that when Phillip drinks alcohol his chemical reaction set's off a craving like opium would. And so it's very addictive. And so I understand a lot about the disease. I understand more about it than Phillip knows about it.

Like with Shane's disability, I felt that there was a lot of pressure put on me to do everything. That he (Phillip) wasn't taking responsibility and so I was resenting him. So I would eat, just not to feel. So I can see with Phillip... how Phillip copes with his frustrations is to drink.

I think it might of.. it probably hurt Philip's pride that he couldn't provide this himself. And he wouldn't go.. he wasn't about to go to people and say, "Look, we can't financially"... because I think it had a lot to do with the fact that, that would make him have to look at his drinking problem, too. I mean, it's not that he was drinking a lot and spending a lot of money. But he was still doing it. And I think it made him really realize that he was having a problem, and that his disease puts the extra strain on our family.

I know that part of me, part of my personality is that I have to say what is there. I have been so used to stuffing things down, stuffing feelings and stuff like that. But I have to get them out. I have to have somebody to talk to... That's just part of me. If I didn't voice the negative feelings... like I'm a very black and white person as far as judgements on myself. I can be very harsh with myself. That's why I need to do it. I need to get it out because once I say it then I'm not as judgmental as when I'm thinking it. It's different. But at least I know that that's what I have to do.

I attend the Al-Anon program. I find I have a lot of support there, practising the twelve steps of the program. Now I'm not trying to be the person that runs the show all the time. And I'm realizing that I don't have to know all the answers and it's O.K. to reach out to somebody else, and recognize that somebody else can help. That's what my coping is. When things have gotten too rough for me, I've talked to somebody about it. I talked it out. If I just can't handle it any more, I get some help. Sometimes in just saying what the problem is, just talking about it, narrowing the problem down to what it actually is... In other words I try not to make mountains out of mole hills... So I got a lot of friends that support me in that way.

I have a sister, she's the one that works down at the flower shop. While I'm down there creating, I'm down there talking away to her... She's more like a mother to me... We had a big family and the older girls had to help out with the younger kids. So we've got a very special bond. She's my best friend. We share a lot of things. I can tell her anything. I know that it's not going to go beyond the walls... She's an excellent person. I feel that I'm a good friend to her, too.

I have another friend that's in the community... That I can share confidences with. She shares both the living with an alcoholic and the compulsive eating disorder. So I have a lot to talk to her about, too. Those are my two main people that I know that I can share everything with.

And then my brother's girlfriend, too. She's a good friend. She's the person that I go out and have fun with... the person that I can let down my hair and just, you know, act silly and talk silly. So I have different friends that meet different needs. It's nice if you can have somebody that you can share it with. Because even though it doesn't help you get rid of what you're carrying, it helps a person to relax about it and put it down for a little bit anyway...

It (attending Al-Anon meetings) makes for a much better relationship because I'm not just standing at the door with my claws out when he comes home late. I hope that Phillip will find help too. The kids will always love their father and their father loves them and I would never, ever, go take them away from him. I would still make sure that the kids would always have their father. I would make some kind of arrangements for them to spend lots of time together. But for right now, as far as me and Philip and our family, it's working out pretty good. But it wouldn't be that way. Not unless I had the support of a group of people going through the same thing.

I go to Al-Anon to help me deal with my feelings about everything, not just the disease of alcoholism... my feelings with my parents and how I was brought up... all those things. They're excellent programs cause they help you look at yourself realistically. Oh I had some friends... I've gotten rid of them. I used to be there with my ear open and just letting a lot of people drain me dry. And I just said enough is enough. It was just that.. I just said, "Look, there's a place where you can go and get help. I'm not going to be your program. You are in a program, a twelve step program and I think that maybe it's time to start using it..." I had to be cruel to be kind. I just couldn't be listening to people phoning up and going on and on. They didn't really want to help themselves, they just wanted to have something to cry about. So I said, "When you're ready, when you want help, I'll show you how I did it... how I made it through, but not until you're ready to want to do something about it." I don't have time for it. So I don't get these phone calls anymore.

Well I feel that without the Al-Anon program I wouldn't have.. our family unit wouldn't have survived because it's just ... I was doing all the same things that every other woman does when they don't understand. But now that I understand and he knows that I'm quite comfortable, I can live quite comfortable right now with the way things are... But I also know that I'm confident, I got my confidence back. I'm quite comfortable in knowing that I can leave if I want to or that I don't have to stay in the situation. I've got choices and that makes a big difference.

7. Demands on Parents

All three families find themselves facing many demands over and above the ordinary demands of raising a family. Moreover, these demands are often more intense and of greater duration than is usually the case in child-rearing. While the fathers in each of these families provide good emotional and practical support, many of the special needs of Bruce, Marianne, and Shane fall primarily on the shoulders of Martha, Anne, and Sara.

Quotes #9

David and I(Martha) work really hard to keep Bruce busy on the weekends; but when you work, you know, it involves: What do we have to do that we can involve Bruce in? And then: Is there any time left over to do something that he might like? Like take him to the beach or take him for a drive or a walk to the park or...

We take Marianne skating and swimming and things like that. We don't allow her to get into a rut. I go two days a week skating and one night swimming. So you know, it's you that's going to have to do it, so you might as well get busy and go and do it. It all falls on the parents' shoulders... I'm busy keeping her busy... It's not that I can just send her down to the rink by herself... others don't realize it's an extremely different situation. If she's going to benefit from it, it's because of our efforts to make sure she gets there and does it.

No, no, I (Sara) blamed myself for not doing it, not taking the time to sit down and read all through the information and uh, you know. Because I just didn't have the time. I was dealing with a lot of problems. At that time I was dealing with getting myself sane again. I just didn't have the time to just sit down and sift through a lot of the information and pick out what I thought I could use. I needed somebody to tell me, here's two or three things that you can do at home. Maybe not even three, maybe two things that I can work at and then try something else. But don't be giving me a whole bunch of stuff that I wouldn't know where to start with... It's not that I don't feel that I'm an intelligent person that could have gone through it and picked out the things that I needed to do. But I just didn't have the time to sit down and figure it out. Not when you're getting it from all different areas, it just can be overwhelming.

When Bruce's friends call it is me they talk too. They want to know how he is doing and what he is wearing today and what he is doing Friday night and so I have had to learn to talk to 16 - 17 year olds... It has been real difficult for me because he can't pick up the phone and call them and they can't call him. But they are comfortable to call David or me.

I'm no hero. There were plenty of days I (Anne) said, "That's it, I am not doing any more. I don't care where she goes or what she gets into. I am not fighting anymore. And I'll keep her home"... Mind you, it only lasted a short while. Then it was time to start again. And you do.

I find Margaret more stressful then Shane... Because she is very demanding. Like she's um, oh I don't know... It's always, "Mom, Mom, Mom..." To get my attention. It's just like, it's almost like.. I know she needs my attention but it's like I don't think I can give her enough.

There are times that I wish I had more freedom of movement in the sense that I always feel that I have to be available to whomever may have Marianne, whether it's school or whatever. I don't feel that I can just cut loose and not be too far away without... a phone call away or something like that. It was definitely harder when she was younger and the boys were young, as well. I didn't have the freedom to go as much as my friends could go... out in the evening or things like that. So definitely you're more confined... more so than the mother of any family unit. I would say a mother of a handicapped child is more confined and confined for a longer period of time.

And we've (Martha and David) been to places like the Society and we're saying look there's a real need for a system change here. "This is not just our problem. Families are running into this." And you just get the line, "Well, you know, if you want to make a change, well we'll have a meeting and we'll all take on a job and..." I can't take on another job. I can't do it. I have no more time to take on another job.

I haven't explored those groups (Brownies or Guides) to be truthful with you. I had Marianne in a catechism program a couple of years ago at the church... I didn't find my reception overwhelming... And I was... usually I'm not one that will back off because my reception wasn't good. In fact, that gets me going all the more. I'll usually admit that quite freely. Two years ago I was struggling here with the school, you see. Trying to keep that on the up and up. And I didn't know if I really wanted to tackle the church too at that time... There's a limit to what you can do and what your head can hold. So I let that go. It wasn't what you'd expect from a church. So there's a real kick in the teeth, as far as I'm concerned... practice what you preach type of thing.

So anyway, we struggled through it (Bruce's illness) but I sort of felt that I wasn't anywhere doing anything for anybody, be it at work or at home. David was feeling the same. And we were getting lots of pressure from the school.

Because, I just can't keep it up. I can't keep juggling it all... something is going to fall apart at some point.

Ya, they (parents of disabled children) have enough to do. They can't do any more. But we don't get a whole lot of support unless we're willing to get out there and fight and work for it.

Respite care would be one of those (special things) that we've had to do. Baby-sitting for us, well, is it ever going to end?

In a matter of one phone call, I got the other two registered in school. To register Marianne was an eight month process of meetings and phone calls. I can call and get the boys into hockey or anything. I can't do one bloody thing over that phone for Marianne. It's a meeting, then there will be another meeting and they take it to somebody else, for another meeting.

Interacting with Professionals

1. Services

Martha, Anne, and Sara, all have experienced what could only be termed "horror stories" at the hands of some professionals. These mothers have been made to feel inadequate, subversive, uncooperative, disheartened, overwhelmed; and to experience ongoing feelings of guilt. On the other hand, each mother also has experienced very positive, supportive, and very productive interactions with some professionals. The difference seems to be related to the particular attitude that the professional possesses concerning the child with a disability or, perhaps, concerning disabilities, in general.

a. Negative Experiences

Quotes #10

Now I (Martha) spent a lot of time last year being on the receiving end of the phone calls from the school... "Come and get him. Take him home. He shouldn't be here."... and all of this stuff. They would always call me first at work. Always call me first... I would get messages or I would be told later by the teacher that she was very disappointed in me in that I wasn't available to come to the phone right away or that I had gone out to a meeting or just horrendous silly kinds of things. Anyway it just got to me. I put up with that for a whole year, practically. We write back and forth in a book about Bruce to the school, just because of his inability to share with us everything we need to know. And I would write, "I'm not going to be around today, you'll have to find David if you need anything." But still they would call me first. I found that very taxing.

And just because of that... and with my new responsibilities this year and under new employment and you just can't get up and go when people call. I just can't... David and I talked about it and he's going to take that on this year. I'm just not returning the phone calls. They'll be forced to have to deal with David.

I remember a six page report from a speech therapist, done immediately prior to Marianne's entering school, that when I received it in the mail, I actually cried. Of six typewritten pages there was not a positive thing in it! It was a total list of what Marianne can't do, not one mention of what she can do. A report like this is extremely disheartening. I already know what she can't do. There had to be something positive to build on. It gave me a sense of hopelessness and total frustration. Why would I want to return to see this professional who had nothing positive to say and no recommendations of how we can help in Marianne's problem areas?

We were getting some help to put in a stair lift. It happened after Bruce became an adult, so we'd made an agreement where... They certainly weren't prepared to pay for the cost of the whole stair lift. They're very expensive. So we split the cost with them. I made it quite clear that they could either send us the money, or we'd pay for it first, or whatever they wanted to do. Anyway some welfare worker, on his own, that I've never even met, who says he's Bruce's worker... his financial worker. (And I've never met this man) took it upon himself to call the company, a local company who was supplying us with the chair, and inform them that this person is on welfare and they were to bill so much to the department and it would be paid. Well I was just devastated... I call once a week, I want to speak to him about what he's done. He won't return my calls... they just start to treat you differently. I just feel that Bruce... or we don't get the same respect now that he's an adult, that we used to get. The same privacy is not afforded us.

I had one professional come here, well not here but out in Dover and wanted me at that time (because she looked it up in a book that the child should be able to learn how to open the door handles for getting in and out of your house. Cause age-wise that book said that). Now, the professional, I mean just had to look at Marianne. Marianne was not even on her feet at that time, although she was two and a half. And she used to jump around the floor on her bum was how she'd get along. So I asked the simple question, "Well how am I going to get her up to the door knob? She can't take the weight on her legs yet. That is what we're working at now... to get the weight on the legs... Oh she didn't like it (my questioning her). She didn't like it one bit and indicated that "Mother was uncooperative."

There was the time that we went to take Shane to see that developmental psychologist. She handed us a book of all these things. She asked me why I was there and I said because I wanted to have an understanding of Shane, where he was "at" so that I could know where to go from here. Anyway she did an assessment on him and then I asked is there anything... could she give me anything that would help? That was my main purpose of being there was to get some information. Pass some information on to people... But she handed me a photocopied... Well, she didn't hand it to me, she sent it in the mail to me. It was really thick and it just had... it was more of a clinical kind of... something that a professional would use, not a parent. I mean, there was a lot of things in there that I didn't understand even... And when I got it, I just put it on the dresser and that was it. I left it there for quite a while. Then I thought.. every time I walked by it... I'd get the guilty feeling that I should be doing something. I should be working with Shane and all this. And then... then I'd say, oh well, I just don't understand. Anyway... everytime I looked at that thing I felt guilty because I wasn't doing anything with him. But I just didn't know how to go about doing it. She gave me the Hanen Early Language Book and said, "Here, do this". And I just looked at it. It was a binder and it had a lot of information in it. You just can't do that to people, just go and hand them something and say do this... And not go over it with them and show them how it works, or how you can bring that stuff into your everyday life. It just felt like it was too much. It was going to be too hard to get the information out of it and it was going to take time from Shane (just learning how to do the stuff)... Anyway, I just would feel guilty about not doing it.

If anybody is sick in the family, I'm stressed over that. Financial demands make my life stressful. Dealing with professionals makes my life very stressful.

Last year, when he entered the senior high they put him in for a bit of gym. But what they did, Barbara, when they put him in a gym class, first they made no introduction to the other students about who he was and why he was coming, in ways that the students could welcome him. We talked to them about that. So then, they went back. They backed up and they tried to prepare the students. They changed gym classes and tried again. They thought they did very well. But when Bruce entered the class, he played on the side lines, while everybody else did their thing.

And another thing they refused to do was put him in classes where his friends were. That was the only thing we ever really wanted, was that he'd be in the classes with some of the people out of his Circle of Friends. And they were taking things that we knew that Bruce would enjoy, computer, typing, music, art. There's a course called, I think "language arts" at the junior high level. Now I'm not sure what it's called at the senior high level. But it's where they would do report writing. And the kids came up with this one at a Circle meeting: Let Bruce come to the first half hour of this class because we write in our journals and he could sit with us just like in junior high. One person would sit beside him 'cause he was drop seizuring in junior high... they'd sit beside him and if he'd drop they'd catch him. So they (the kids) had no problems with Bruce. They come up with this plan at senior high, that he could join this English class for a half hour, while they wrote in their journals. And while they were writing they would read to him what they were writing because he loves to be read too... You know, and it's not an instructional time. So it's not taking away from anybody. And Bruce's special ed. teacher didn't feel he was ready for that. And by the time you fight the issue the semester's over and the kids have gone to something else...

I would say in the four months we (Martha and David) were probably there (meeting at the school) a couple of times a month, on average. And then when he came back (from hospital) he didn't go to school right away. He came back from hospital in early May. We got a phone call. As soon as they heard he was back we got a phone call saying, "We trust that you're not sending him right back to school. He's going to need time to recuperate..." I always constantly felt like people were trying to insinuate inadequacies on our part, constantly. So it wasn't just visits to the school. It was all the other stuff that they had us running around doing... Just totally exhausting us. We brought him back and had no intention of sending him back to school after being six or seven weeks in hospital. But they wanted to make sure that we had no intention. And then when he was ready, we had to have a meeting before he went. We had one more meeting after he was in school and there was one more after he came out of school. So that was from mid-May to the twenty second of June. We met a lot.

I think they have the philosophy here that... Well I know for a fact that disabled children are probably the lowest priority on a list here. And if it's a child just with a speech impediment or something, well, they can work on that and see some success. But if you take a child like Marianne where you're basically trying to teach her oral language... that's a big job. That's a big job, and they don't have the time or the resources or I think what it boils down to, is there is no interest.

A lot of the professionals you deal with... you come home with the feeling of being disheartened. Of the majority of them I have dealt with I can honestly say that. That it's disheartening.

I think I've said most everything, some of it in a round about way. I just think the system stinks. It's certainly not responsive.

b. Positive Experiences

Quotes #11

Sue Kinaschuck is the family support program worker. She has been an excellent support to me (Sara) right through. She'll say, well that might be too much for me or she'll say, well are you interested in this? and she'll give me information... if there's a workshop or something... that she thinks I might be interested in. If I get too much stuff or if there's a whole bunch of stuff to look through, she helps me to look through it and the decision on what would help, as far as what would be the best. She'll say, we don't want to get you overwhelmed with a whole bunch of information. She helps me to sift through a lot of stuff.

The principal was a really welcoming person and wanted to try this out. We (Martha and David) sent him to the next province to see some of the stuff over there, where they were integrating kids successfully. He went for three days. She saw some wonderful stuff at the senior high level and came home all excited. But he doesn't have a lot of support around him.

I just don't believe that a place like the general hospital could ever operate like a children's hospital, where they work in teams and where parents are so vital and important in the process of getting well and getting kids better again. They (the children's hospital) just make you feel if you weren't there, things just would not go, as well... They really value family.

There's Bruce's family support worker or whatever Betty is. She does her best in her limited authority within the department to try to get things for Bruce. She will go to bat. She will take things up the line... So I have to say that Betty has been helpful. The difficulty is that once the wheels kick in, in terms of processing how things happen, Bruce just gets lost. I have a big problem, with how things have to be processed in that place.

Sue Beck one of the speech pathologists in the Hanen Early Language Program, brought that book... that green book that the other speech pathologist went and handed to me... She brought that alive. She showed how to integrate that into my life...

Before he (Bruce) turned eighteen, Betty was the only person we had to deal with. She took care of everything. And you could handle things financially the way you chose. I mean if you wanted to be paid once a year and take your money, you could take it. It doesn't work that way anymore. I just find that it's more dehumanizing now than it used to be. But certainly she is supportive in saying, "Yes, (if you say you need this) we believe that you need this." And that, I guess, comes from her experience of working with us, to know that we're not out to rip off the system or to take things that we don't really require. So she's somewhat helpful. Um, other than that it's sort of just friends or people who care about us or care about Bruce. We don't have a lot of people paid to be in our lives that we find supportive...

We stayed at the Ronald McDonald house in Regional Centre... That was great. It was a really good relief to know that we had some place close to the hospital, to stay. I (Sara) had lived over in Regional Centre before so I knew my way around. We went over. I remember we had to be over there and it was a snowstorm on the way over. My other sister and brother-in-law drove us over. So, there was five of us going over and we landed in Regional Centre in the middle of a snowstorm... All this fun stuff. Any way, we got there and we got tucked in. Shane saw Dr. Curley the next day. Dr. Curley is just a God-send. He has such a good way about him. Everybody just loves him.

The family doctor is great with Margaret, too. I took Shane out there to make sure whether he had an ear infection or not and to see if his ear infection was cleared up. And Margaret coughs and says "I got a cold; Dr. Wills". And he says, "Oh that sounds like a bad cough there Margaret, I guess I'd better check it out". It's so sweet. He realized that she needed to have a little check herself.

You see, the best thing about Elaine Rhodes, Shane's one-on-one teacher, is that she's a parent of a disabled child. She knows. She sits in on case conferences for us and she'll say, after we get out, look Sara, I know exactly how you're feeling. All the stuff that they're saying. Everything that everybody was saying was their own little interest. Out of all the things that they say what do you really feel that we should work on? And then I'll say well, you know, maybe this... She's very supportive that way.

Our pediatrician is a good support for us. Unfortunately he's retired so that's a big loss right there to us.

The pediatrician I found was excellent at that time. The pediatrician, who was supposed to just be looking after the baby, had to take me on as well. From him I got a fair amount of support. Fortunately he's the pediatrician that was in practice for thirty some odd years and has dealt with this situation before. He knew a lot of children with Down Syndrome so that he could give me a somewhat positive attitude about it. Had it not been for that one particular pediatrician, I don't know where we would have turned or to whom we would have turned. The pediatrician's words to us were, when I asked him where do we go from here... I remember specifically asking him that... he said, "You take the child home and you treat her as normally as possible."... Sometimes people ask, "Who gave you the most encouragement about your child, and the most support for the new parent?" I would have to say, "this particular pediatrician."

The speech therapist I have now is Susan Jones. She also knows the things that we need for Marianne. Susan wanted to have her (Marianne) the first part of the year down at Pine Hills School so she could help get the program in line with computers and things... I experience an awful lot more of personal effort put in from Susan to try and help out with Marianne's communication ... She starts with a positive. She's not going to build you up with a lot of stuff that you know is a whole lot of baloney, that's for sure, either. She starts with a positive and works from there, rather than the negatives.

And that's one of our (Martha and David) other fears... Really that hospital's supposed to take kids until they're sixteen. They will take kids I think up to twenty one, given certain criteria and Bruce meets every single one of them because of all of his special needs and things. But we're going to lose that support within the next few years. That's scary. Um, Dr. Curley has followed Bruce well since Bruce came home to live with us. He's very supportive. He's the chief neurologist over there right now, I think. Although they work in a team over there, so it's really hard to tell who's who. They don't sort of get into these I'm the boss sort of thing. He's been around and worked with Bruce for a long time.

They (early intervention/day care personnel) always kept you abreast of ... "look that's not working. We're cleaning the slate on that. What we're trying to do with her is not working. It's probably us or the way we're doing it, or something. But we're scrapping that and we're going to try another whole approach on that." And they didn't try and take her and stick her into their system. They kind of made their system work around her.

She'll phone up and say things like, I think it might be time for a case conference. What do you think? And I'll say, when was the last one? And she'll tell me. She gives me all the information that I need. She makes sure that I have it. She keeps me up to date on what's going on. For example, For this conference, here, the Intervention Conference: she phoned me up about it. But financially I wouldn't be able to go by myself. She said don't worry about the finances part. She said, I'll work that out. You just see if you can arrange to get the time off.

2. Education

The services that these families are receiving from educational institutions vary greatly. All three families want their children to be educated as much as possible in the "mainstream" of available educational services. All three families want their children to receive educational experiences which will meet their developmental and educational needs. All the families feel that mainstream education has a responsibility to make the appropriate adaptations so that their children can be included. Bruce, the oldest and probably the most severely disabled child of the three, is currently having the most difficulty in receiving appropriate educational services. This was not always the case. During his junior high school years, Bruce's parents were very satisfied with what the school was offering Bruce.

Marianne has had much more consistently appropriate and "mainstreamed" educational experiences than has Bruce. As well, she had a very successful and satisfying early intervention and Kindergarten experience, provided to her through day care. Marianne, of course, is younger than Bruce and has probably profited from all the children like Bruce who have preceded her and the pressure from their parents, which have helped to "shape" the educational opportunities which professionals are willing to provide. As well, now that many of her health problems have been alleviated, Marianne is probably the least severely disabled child in our study.

Shane is just beginning school. He has had a very successful and satisfying early intervention experience at day care and the mechanisms are in place to help him make a successful transition to the mainstream of his local school. The exact level of Shane's disabilities cannot be accurately assessed, as yet. But it is fair to say, I think, that the notion of placing him in a regular grade one and maintaining him in the "mainstream" of his school is not a new idea to the school personnel with whom his parents are interacting. They seem very supportive of Sara and interested in welcoming Shane to grade one.

Quotes #12

They just set up a regular special education model, you know, special ed class in the regular school, making it very difficult. Plus they're high school teachers who aren't, in my opinion, getting the leadership they need as to how to make that school a welcoming place for the kid with disabilities.

Um, I would say that from September until December, we (David and Martha) were probably there (at the school for meetings) half a dozen times. No, no, they called us in before school started, we were in the week after school got going, we went back the end of September. Ya, well, we were in a lot. We were in again in October. There were concerns that maybe... stuff around seizures and Miss Maxwell wasn't sure if she was dealing with his seizures properly.

Friday they said he (Bruce) fell asleep on them. I thought, here it goes... Like I said to you earlier, that's Bruce's way. That's what he can do. He can just shut down on them. He's real good at it. In fact there was a number of occasions last year where they would call and say, "Look, he's out of it. He's sound asleep. This is not productive. Come and get him." And the minute David would walk in the room, and say "Bruce", he'd get up, start laughing at them and run out the building. And them just looking, you know.

Well we tell them what we would like. And it's not just based on what we want. I mean, it's based partly on the fact that we feel we know Bruce better than anybody in terms of what he needs and how best to meet his needs. But we've gone great lengths, Barbara, to ensure that we're not just airy fairy crazy people... that some of the stuff that we believe are needs of Bruce's, are in fact, justifiable. We've gotten things from places like the J.B. Children's Hospital and his speech and language pathologist here. And I remember the speech pathologist, here, initially talking about Bruce's apparent inability to communicate or peoples' inability to "read" what was really happening and that we needed to start giving Bruce things like choices... When we relayed that to the school, they said, "Oh my God we can't give him choices! He'll choose not to do anything." They made an assumption that Bruce would just choose to be lazy and do nothing. In fact they found out the opposite to be true.

Oh day care was excellent. They had a good group of people that were very knowledgeable; but yet, didn't shove they're knowledge down your throat. They didn't always want to make themselves look like a professional telling you what to do. Although you knew from the very time that they opened their mouths that they knew what they were talking about... But they always.. they could spill off a lot of things to you. But they would always say, "Well what do you think?" Like they gave you chances to participate.

They (day care/early intervention) changed the system to accommodate Marianne, whereas I don't see that in the schools. She has to fit into their specific system, somehow... And I mean these are the educators with all the education and the brains. Why are they expecting a disabled child to fit into their system? What can they do to make it easier for the child to fit in? "You're the one without the disability. Don't put the onus on the child to fit in!"

The grade one classroom that Marianne was in, with the regular teacher and the teacher assistant, signed to the class. They took it upon themselves to teach sign language right in the classroom... Ten minutes a day was allotted to sign language, to the point that those children, at the end of grade one, were almost fluent in sign language. They amazed me how they picked it up and they loved it. The same thing is carried through in the grade two room but that's only at my insistence that it be continued. They did want to drop it. They figured if they forced her to use oral language that maybe that's the mode. But there's no sense in forcing her. She depends on her sign and I think you have to learn this stuff, it's as simple as that... So don't take away from her what she's got. Keep adding to it... don't take away what she's got, is my philosophy. So they do the signs.

That's, I guess, why I (Anne) got along so well too with the grade one teacher that had her for two years. She would always show you, "Well look. She did this and she can do this really well. We are very pleased with her ability in this area." And then (as the teacher progressed) she'd say, "But, of course, you know, math skills, she doesn't have those yet and maybe she won't." You know, that type of thing. She gradually came down and got out everything she had to say but she didn't meet me at the door and say,"Well look. She can't do this and she can't do that." It's a whole different approach.

He (Wayne) did go out (of the classroom). Of course the teacher in Wayne's room was very good, too. He didn't mention the fact that Wayne went out or anything and had to help with his sister... He just... If he felt Wayne had to do that, he let that go.

I find that the day care... They're really great for making me feel that Shane is going to be integrated into the community because, they're so accepting.

I'm finding when I approach the school... the principal of the school, he seemed very supportive too... He's wanting to get together to make some plans for Shane's entry into regular grade one.

Daily Living

1.Struggles

Most, but not all, of the struggles these families face in their daily lives specifically associated with their child's disability, have to do with education or other developmental needs. There are some struggles, as well, trying to find adequate information about their child's disability and finding optimistic possibilities for each child's future.

Quotes # 13

We send them (the school) video tapes. We're just constantly trying to do something. So if it's not a phone call from the school or bringing him to the doctor so that they can hear it from him (that we're not telling them lies) or... Because there's always insinuations that we're keeping things from them... But it's just so exhausting and what we were doing was getting caught up in their game and having no time. Bruce just had a total.. almost non-year educationally, last year. And there were times when Bruce was "up" and ready for learning.

Back in June, an update on Bruce's lifestyle plan was done with some help from the folks at the technical school. Miss Maxwell (Bruce's special ed teacher) did agree to check out a couple of courses for Bruce. On his typing, she would look into it, but she was not supportive. To me that's just setting it up to fail. When you don't have a teacher coming forward with a very positive approach to a regular teacher, you know. These teachers have been in this school forever and they don't know why "these kids" are here to begin with. They are very much afraid... So anyway, she did make the commitment to check out two or three courses to see if... Two of Bruce's friends, Marie and Paul were at the planning meeting. It was great to have them because Miss Maxwell would say things like, "Well, he couldn't really go to typing class because it's usually always full." Every time we asked by the time she got around to checking, the classes were full and there was not room for Bruce. So we said, "Well, this year if you could supply the desk, we would supply a typewriter. And there must be three square feet where you could put Bruce in a desk." Kind of a back up but, you know, we run out of tact after a while, and we just say things. Anyway, she promised to check it out and she felt that if he got too excited that he might scream or something. But Marie and Paul said, "Well, that wouldn't matter, because once you get your instruction and everybody's banging away and typing, nobody would hear Bruce scream." So Marie and Paul are really good to have there. They're a good support. Anyway, Miss Maxwell lost that little battle and agreed that she would have to go and check it out.

But I can remember my original request for respite care for Marianne. We were told if you want to go away for a week-end or a week or whatever, Forest Home was our only option. That was it. That was all. Well, that's not for us. That's not what we'll be doing. So if I want the weekend off you're telling me I have to put her over in the institution and tell me to drive away and tell me to have a good weekend? Now you've got to come up with something better than that... I don't want it. I don't want it. Take your worker who has qualifications and bring her on over here. She stays here with school available to Marianne. There's a car available to the worker. Let the trained worker come to her home and look after Marianne in the community. And then let me drive away and you can say to me, "Have a good weekend".

They really don't exert any pressure (to move Marianne out of the school) at this point in time. It has been said to me, though, if... if with maturity, if she's not going to fit into a grade three classroom, we have the option of moving her up to grade four, or whatever. But I think they realize now, after two years of me being down there, that I'll give them the decision on that. I'll decide on that,... what I want to do. Definitely I would say they wish that they didn't have her. In a community this size it just amazes me that she's the first child with a mental disability to be enroled in that neighbourhood school... We're not talking about a new school, by any means.

You know it's just that extra... I mean It's an awful feeling when you're preoccupied with this child with this disability you think of nothing else. And no matter who you ask, they know very little about it or what they do know is very gloomy. You don't want to hear it, anyway. I don't know how many books I took home here and shut the cover after the first page.

So we (Martha and David) have had to spend a lot of time just sort of being taught that these behaviours mean things. They really mean things and that people just don't do things for no reason. So to get to what things mean and tell Bruce that we know and give him what we think he is looking for... And it has really changed his life. Even that little bit has turned him right around. He has become more outgoing and more assertive.

Of course we're tired. Things are better now though, since Bruce is well, and sleeping at night...

I spent nine months and I went right to the top in Social Services to get day care covered so that my child could go to day care And in the end, the answer was so simple and so much easier. Through family services you are entitled to 21 respite days a year which is 63 day care days, compared to their twenty one days that they had been willing to provide. You know like, give me a break! The answer was so simple and yet they made it so complicated for me. Nobody would say, "Well let's do this". It wasn't until I fought and just kept being the squeaky wheel all the time that I finally got somebody to put on their thinking cap and come up with a solution. Cause I was saying, I want a solution. And I don't want it to be too late. Right now they have a waiting list for tutors. They can't provide the tutors for the day cares. Kids are waiting and there is no priority list. It's just first come first serve... it doesn't matter if your child is severely disabled or whether the child has no disability and they just feel that he would benefit from tutoring.

But I did have Marianne in an art class... In fact one parent said to me one day, "What do you think she's going to learn here at the art club?" I said, "She's probably never going to make what your daughter can make. But she's getting exposure to other children and the children have exposure to her and, hopefully, those children will grow up with a better attitude to the handicapped than you are displaying right now!"

I'm going to have to give the church a whirl, for example, again. Because ah, I want her, now, to make her first communion.. I don't think it (the difficulty) will be the two priests at all. It will be just that she probably won't want to take the host. She doesn't like taking something new that she hasn't had before. But that's another one I'll have to go through again.

Now the speech pathologist that Shane was working with first, she couldn't communicate with him... I could see that in their trying to communicate. And it was a waste of time. Because she just did not seem to have the skills to work with a non-verbal child... Now she was good with children that had speech already. But when it came to the non-verbal child she wasn't very good. So I wrote in and requested that I have another speech pathologist because I felt that the speech pathologist that was presently working with him... I didn't feel that she and Shane interacted that good. I felt that maybe, non-verbal was not her area of expertise... I got a new speech pathologist. I was down in Capital City and I was talking with the day care, with the head of the day care. Fay Clark, the head of the speech pathologists, she said.. Is that Sara out there? And I said yes and she said I've been meaning to get a hold of you. I've been trying to phone you. She asked me to come into her office and she wanted to know just what it was that I didn't like about this speech pathologist and that the speech pathologist was very upset with me. She took it very.. like on the defensive. And I explained to Fay, I said it wasn't that I didn't think she was a competent person. I just felt that her non-verbal skills weren't... the skills that she did possess weren't enough for Shane... I wasn't putting her down. I was just requesting that I have somebody else that I felt would be much more suited. There was another speech pathologist that I knew was available so... I didn't think that it was going to be a problem. But she was quite "put out" that I had written in a request so... If she had a problem with the letter she could have called up and said, "I'm just wondering why you don't feel I should work with Shane", or maybe she could work on getting better with non-verbal kids... And I did it in a way that... I make sure that it was done in a way that wouldn't put her out. I wanted her to know that it wasn't.. that I wasn't putting her down as a professional... I just felt that Shane had more needs than she could address at this time. I didn't mean to offend her or anything. Anyway, I know that I did offend her because I saw her in the store after that and I said "Hello" and she just turned her head and I know she heard me.. Sometimes those things happen and you'll be O.K. (in the relationship). But if I wouldn't have done that (written the letter), then Shane would still be with the same person and I would still be having that frustration that I was having before.

2. Needs

Martha, Anne and Sara expressed many needs during the course of our interviews. While they expressed a wide range of needs, their statements indicate many needs in common. All three mothers indicate that they could use some hands-on support and respite, in addition to emotional and verbal support. Anne and Sara state that they would value an opportunity to express how they feel in the presence of people who would understand their situations. They also indicate a desire to talk with other parents of disabled children to share their daily challenges as well as their feelings. All three indicate a need for accurate information and some shared advocacy with people who do not face these struggles on day-to-day basis. All three indicate a need to work outside the home as a break from their family demands and as an opportunity to be present and functioning in the adult world. Sara, and to a certain level Anne, indicate a need to resolve personal barriers associated with the disabilities and early illnesses of their children. Sara is especially touching in her expressions of a need to talk about her feelings concerning her son's disabilities. All three indicate a need to fulfil their own personal needs as individual human beings, apart from being mothers and managers of households. Lastly, Martha poignantly expresses a need not to be exploited by a system which does not adequately recognize the contributions to society as a whole (and saved tax dollars) which care-givers of disabled adults provide.

Quotes #14

And there's always this um, I'm not sure what the word is but it's like you're fighting against time. You feel that time is running out and things aren't getting done... you just feel really helpless to be able to get everything that you need. And not frivolous stuff. To us it's... He has rights that are not being awarded him.

I could sit here and talk to a friend of mine about the problems I might be having with the T.A. or something at school... Well they're not in that situation. They respectively listen to you but they're not hearing what you're saying. And it comes to the point that if that's all you're going to talk about to your friends they get to the point where they don't want to listen to you anymore anyway... Because they're not facing that situation. It's not a lack of interest, it's that they're not involved in that situation. So it means nothing to them in that sense.

If you were with a bunch of professionals, if you're dealing with a lot of professionals, you do feel like you're on the one side and they're on the other side. And to be able to sit around in a group of parents that are going through the same things because they have a child with a disability... It doesn't have to be the same disease or anything. They still go through the same frustrations or the school board's not accepting your child and you'd like to punch the principal in the mouth! You know, that's a real... feeling. And a lot of parents get guilt feelings about that. You know about getting that mad, that angry.

You can talk to your friends but they don't understand the way another parent would understand.

I think there's a difference between listening to somebody and hearing somebody.

I know when Marianne was born and they came to tell us, if I had somebody that could have said to me (whether it be a nurse or whatever), "Things won't be that bad. I went to school all my life with somebody with Down Syndrome". That would have been a big "pick me up".

I've often wished that I had help to clean the house and for people to come in and help me with that. But that's just another expense and it's certainly one that the department of Social Services isn't willing to pay. But that's another... I have quite a number of gripes with them. I think they abuse, especially parents of disabled adults. It's like slave labour, looking after adult people with disabilities.

School wasn't even focusing in my mind at that time, (at Marianne's birth). There would never be school (I thought). There would never be birthday parties. They'll never... There's a whole lot of "nevers" that was going through my mind. You know Brownies, I thought she'll never go to Brownies. She'd never... impossible.

That's dealing with the family thing. The everyday things that are different. The fears that we are different. The fears that we have inside and stuff like that. We don't talk about those. I find that one thing I would like to have is a support group for parents that are saying, you know, when their child has been crying for twelve hours straight that they feel like being able to say I could just take him and shake him... and make him stop. That's O.K.. that's a feeling. We sometimes feel we are bad parents for feeling that... That's a real feeling that a parent has when their child is screaming and you don't know what the child wants or they're pushing something at you and can't make it fit together and you don't know how to make it fit. The child won't accept the "no" and the feelings you have that go along with that. You can't help him. Where can you share that?

Ya, I think if we (the various groups) all got together and just said let's have a group of parents just a place where you can go... start up this group that's totally different from the Society and from the other groups... Just a group where you can just go and "share".

It's just to be able to sit there and talk about some of the things like... I don't know, just the frustrations of dealing with doctors or with anybody. Just be able to go and say I feel like everybody's ganging up on me... Or just being able to go and say it makes me feel sad. I saw two kids running down the road and my son was standing in the driveway wanting to go too but nobody asked him to go, and how it made him feel inside... to have that happen.

We could be there swimming with other parents of disabled kids for the hour and all we did was growl over one particular issue that we may all have faced, whether it's a school problem or something like that. Then another week it may be entirely different. Maybe something really good happened. Something was turning out right. So we talk about that. It's just... because we're in a similar situation and those are the people that best understand... Somebody else that knows exactly... "Yes, I went down that road. I was where you are, two years ago," kind of thing...

Yes, I like the swimming and I like... you have that contact with people with the same everyday day to day situation that you are in. I like that part of it; but as far as skating I'm just there because I have to take her and I have to wait for her... I usually sit and watch the kids skate for a while... I don't get too excited on skating day.

Life waits until the weekend. A few days until we get rested up. And it still gets overwhelming. As I said to you last night, I would dearly love to have a neat and tidy house but I can't. Unless I'm prepared to allow someone to invade what I consider my privacy and come into my home and clean up after me. So far I'm not prepared for that. I'm not ready to say that I need that much help yet. I'm sure it's going to come. That day, I know, will come. Because we have no vision of Bruce leaving us or living anywhere else. This is his home as much as it is our home. And God forbid we should turn him over to a group home. And so what's going to have to happen is we're going to have to open up and accept some more help at some point. We know that. It's just not yet.

You know there were times when even though you were sort of going all out and Bruce wasn't feeling well, you needed somebody to help meet your own needs too and I sort of felt a real imbalance, like a major imbalance.

I took the summer off and really needed that. Because initially when I took time off, I thought, I'm not sure if I want to work anymore. Like I'd gotten to the point that I didn't know if I could handle it all anymore, because it had all just been too much. I thought to heck with this. We'll just live at a different standard. We'll just, we'll make do. Because I can't, I don't know if I could handle it anymore. But time away gave me some perspective in that. Now, I want to work. I know that at least for the next little while, I want to try to continue to work. I want to try to meet some of my own needs, too.

I'm going to miss my few hours of work each day, definitely. I hope to find something again... because it was good therapy for me, too... This is what I mean when you have to work outside the home. It's that space of time that you can forget about... Well I got speech therapy on Thursday and... You can forget about that when you are at work. You have three or four hours of somebody else demanding something else of you. So that's gone out of your mind. Whereas when you're at home your calendar is just basically appointments and things like that.

Sometimes I do 3-D pictures... I need that. I know that. That's part of me. And so on a Saturday afternoon, after work's done up, I will run down to my sister's for an hour or so and just make something. She does all kinds of crafts and stuff at her flower shop. I just go down and I'll make something and put it out on her shelf, so she loves to see me coming. I have to do that... It's a creative side of me that needs to express itself.

Sometimes I get frustrated because he's at that stage where he's pushing, independence. Push Mom away. He doesn't want any hugs right now, and that kind of thing. But I still want to hang on to him. I just want to hang on to being close and stuff like that, cause it's, it's just been so neat. Cause I didn't have a lot of connection with him when he was younger.

But it's the way you figure things out. You have to go and check things out and you have to be prepared for not always getting the answers. But we find out what the answers aren't. And maybe through all of that you get some of the answers to what's medically happening with Bruce and what we might expect. But it's still... David and I are just out there and we're fighting the system. Things are starting to happen around the school and getting some people to rally and help support, but you wonder how much you get out of just volunteers coming forward and saying I'll go do that for you. How long will they do that for you? Where's the safe guard there? That whenever you need it, it's going to be there?

At the conference there was a drama group (that) put on a drama from Newfoundland. They did some skits and some singing on different aspects of what parents go through. It was about half an hour or forty-five minutes. Within that time period, I went through about, I don't know how many emotions. It was just like.. I was watching it and all the feelings came back that I had suppressed, because you don't have anyone to talk to about them. They all started rushing out at once and it was just like... I couldn't believe that I had that many feelings bottled up inside me because I didn't have a place to really talk about them where somebody else would understand.

There was a lot of people would phone and a lot of prayers were said and masses were said and things like that. But there's a difference between support that happens to be just given verbally... but there's nothing wrong with verbal support. You need that too...

I don't have a lot of people pounding down my door saying "you want me to take her for an hour?" or "I'll take her some Saturday evening or something." I don't have any of that. I don't have that kind of support. The only hands on support that we've ever had is what we bought and paid for...

I could use a little more of action. Actual hands on type of things and...

If anything that I have learned out of this is that if anybody came to me and said they have a new Down Syndrome baby, the first thing I would offer would be tangible support... Like if you want to go shopping on some particular afternoon, you drop the child here, and I'll look after it. That type of thing. People need that and there's not an awful lot of it.

3. Changes That Bring Hope

In the lives of each of these families there are reasons to be hopeful. While the number of positive changes that can be seen are probably more abundant for the younger children, Marianne and Shane; it is possible to see hopeful happenings in Bruce's life, as well. These hopeful signs lift the spirits of each child's mother.

Quotes # 15

But you know we've done our best to try to open up as best we can to the people who make it easy and that's certainly not family. But um, people like Mary Winston have been extremely helpful to us. If times got really tough, Mary would certainly be there. She'd be somebody to talk to, and somebody who could... somebody who had compassion but yet was removed enough to be able to say, "Now wait a minute, here. We should look at what we can do that's going to get you what you want." Because you don't go and cry on Mary Winston's shoulder. You come away with things that you can do, positive things to help change and get things more the way you really want them to be. She's been a real big support.

And another thing is, that I don't think about Bruce. I don't think about school for Bruce. I get in there (work/job) and I get so busy that it's not possible, plus I guess part of it's knowing Bruce is probably O.K. right now. I'm quite concerned about his program and how we're going to find time to make sure that he's got a quality program now that we've got everybody convinced that he's well again. So there's a lot of that worry gone too, which allows you to be freer, to enjoy what you're doing... so she did some video taping to show to the school. And one of the instructors from the college... He's helping take some of the load off of us. He'll meet with the school, and because, like I said, it's like oil and water at this point, he will introduce the video taping of Bruce. Estelle did a wonderful report...

So Stewart, if you ask me, he's supportive... He's another unpaid person. He's volunteering to do this and he's going to go forward with Estelle on this report, with the video tape and see if we can't get off to a positive start about some approaches with Bruce. The taping is wonderful stuff. Bruce is doing all kinds of neat things and he's working really hard. The really interesting thing that I observed when I watched the tapes, is that it's not so much what you do with Bruce it's how you do it... If you have a good relationship.. if he knows you care about him. It's just like everything else, if he knows that you care about him, (even) silly boring things like putting beads in a can. He'll do it even till the cows come home for you.

It's great to see this new material. Videos, too, that are out now... Give me a chance. Things like that. The child's first, I'm a baby first... that type of thing. It's what we needed.

The service that I received at the day care was absolutely wonderful. I had no problem whatsoever. I reached out to the day care myself because I was at home with her. At that time I was doing physiotherapy. I was doing speech therapy, I was doing occupational therapy. And when I wasn't doing that, I was sitting in the doctor's office for an appointment, to the point reached in my life where I said, if somebody doesn't help me with something pretty quick, I'm going to lose my mind.

It's really neat. I'm seeing things happen more and more. We were at my brother's place and Shane was cranky and crying and there was me and Margaret and Shane. My brother picked Shane up and Shane put his head on his shoulder, and my brother lay down on the couch with Shane on top of him. And the both of them fell asleep on the couch together. And I thought that was really nice you know... It was nice to see that my brother cared that much about my child to not let me always be the one to see to Shane. He just comforted him. It was nice to know that there is other people that can comfort your child.

Philip's sister in Summerside is really good with the kids. She's so extra special careful of everything. She makes sure... I'll take them there for her to baby-sit them every once in a while. She makes sure that he gets his medicine on time. She's the type of person that would go right by the book... Because she's so capable I know that when eleven o'clock came, that medicine would be in my child's mouth. I know I don't have to worry about things like that, or if there was an emergency it'd be that she would have him to the hospital. She's just that type of person. I feel she's very capable.

4. Strategies

These families and these mothers are problem-solvers. They have developed many strategies to help their children grow and learn and to be involved in the mainstream of life and to help themselves survive the demands put on them.

Quotes # 16

I get mad a lot. And sound off. And in fact... it has worked. I mean, if it were not for all of our pushing and sounding off, Bruce would still be sitting back in the junior high school. The classic (traditional) high school would never have opened (to him).

There was a couple of us that started it (the swimming program) and approached the hospital to see if they would give us the pool... It's small. It's a relatively small pool but the water temperature is terrific.. We're talking at 98 degrees. It's wonderful. We'll never want to go to another pool. That's the problem... (We swim) over at the hospital pool. We (Marianne and Anne) The kids love it and then I have a chance to talk to the parents while (we're) in the pool... I like it. It's good for both of us.

I was the chairperson for the Provincial Society Education Committee. I know all the superintendents of the School Units and the head of the Teachers' Federation. I met them all and... I've met the Minister of Education and the Deputy Minister. And I know who the guys are that make the wheels turn. So they're no strangers to me. I know that I'm not going to have a problem in either one. Because as far as elementary school, integration is fine. I might have a problem once he hits Jr. High because they have a segregated class and once they hit high school it's segregated. But hopefully, by then, that battle will be won.

I'm a firm believer of acknowledging the need to get away. Parents can't be everything to their children... You have to look outside. You have to get the supports that you need. If you can't get them within your family, you have to get them somewhere else. And you have to be realistic about things. I just felt that in order for me to stay healthy, that I was going to have to have some time to myself too. So I'm very much a firm believer in respite care, in having somebody to help.

You always have (when talking with other parents of children with disabilities) that kind of safety net where you can say, look your fella's in grade four. What did you do in this particular time? Did you have that problem with him in school? or something like that.

Well I just take a problem... You've got to distance yourself from it, emotionally. You have to get rid of all of the things that tie you to it and say O.K., this is the problem O.K.? And what's everybody's angle? What is everybody's interest in it?... Even if we do have to go through A.C.T.H. I know, now, that the second time I got smart. I went and got a nurse to come in and give him his needles. And I got "emergency respite care" for somebody to come and stay with Shane while we got away... I found that when he was crying and "going on", it was so stressful for everyone of us. We were just taking turns leaving the house all the time... Where if I can get someone to take him out somewhere and we stay at home or we can go and he can stay home... It's necessary at those times. You have to get away. You can't be around and you... you still have to feel like we're a family. So, therefore, if Shane has to go out for a few hours because he's being very, very cranky during the treatment, I felt it was necessary... And then when he came home, we dealt with it. But it was a rest. That's what it was for us and my family. But you learn. Trial and error. You go through the nightmare once and then you learn how to make it better the second time.

Right now they're only giving my son thirty hours of tutor time at the day care and I would like to have more. But I'm not going to go and fight because by the time I fought to have it all done and put myself through all that aggravation the time would be up and he'd be in school... So, I'm not going to go through nine months of aggravation... There's times when you fight because you've got the time to do it. And you have to do it within that time.

But one of the things that David and I never do is go to any meeting about Bruce without one another. We do not do it. Because you can always... If one's going to "lose it", the other one can maintain composure and think about what to say next. And I find that to be very helpful, to be together.

I always keep Sam abreast of what's happening as far as any problems at the schools or things like that. So that he's well aware of what's going on...

I noticed in the last year myself going and trying to include him (Phillip) because I've just automatically... right from the first... I took over and just did everything that was necessary and left him out. Phillip had never been with Shane when he had a "cat scan". Well there was a time... (When Shane needed to go for a "cat scan"). So at that time I just said, "Now is my chance". I'll make sure I'm busy that day with something else. Phillip wasn't working at that time and I knew that he could do it. So I sent him.

Middle school is six years from now and I'm not going to worry about it right now. I'm doing things to familiarize myself with the whole system and then I've got all the contacts that I need to have. It will probably be a different government in six years time. We don't know. I know how "the system" works.

Her frustration level was really high. Mine was really high because I didn't understand what the child wanted. So that's why we got into the sign language. We had a tutor come here who was deaf and mute... We immersed in sign language right away. Because the tutor communicated only in sign. It was a real good way to learn because you had to learn sign or you didn't know what the tutor was trying to get across.

One thing I don't do and I would say Sam, too, is we don't ignore. We don't ignore things. Certain things that she has done or tried to do which were unacceptable behaviours, we never ignored. We corrected unacceptable behaviour right away.

I love to have people come. I used to have a real conflict with my mother, for example, "You never come to see me" and I'd say, "Mom, I'd love to see you but you'd better come here. It would be so much easier." And then that got worked out the same way with some friends. It's easier to just... if they'll just stop by, or have chats on the phone...

We're trying very hard this year to get off to a good start, to keep things positive. We got a lot of his video taping of his summer program this year. Which was much more educational looking than in past years.

I wanted Margaret not to feel that all my time was spent with Shane. I knew that I needed help in order to make the balance so that I wasn't giving all my time with Shane and not Margaret... I realized that in our family we're going to have that extra support in order for us to make it... (So) I started taking him out to a lady's place just a couple of hours a week. Probably two times a week or something like that... Let me see, how old was he? He was about two when I started taking him out.

I don't structure things at home. I do the things that are more just a part of our routine. I find that it goes a lot better, because when I first tried to do the teaching, I had Margaret on top of me all the time, wanting to be there because I was working one-on-one with Shane. I didn't want to be always pushing her away and saying "No, I have to work with Shane". I realized right then and there that I was going to end up with a very resentful little girl. That wouldn't be good for Shane because she'd be resenting him and their relationship... Shane needs Margaret.

I found out that there was a family support program. I contacted the Dept. of Health and Social Services and they told me about what they did. A support worker came out to see me. She did an assessment on Shane and then we talked about doing some visits.

I try to work around them. I feel I have done that in my situation at school. The principal is not supportive of the endeavour of integration, and he is just not going to be supportive. Anyway, I worked around him rather than through him.

I'd say we're pretty good at family communication, but I wouldn't say we got it "aced" by any means. I think the boys are very good to say to you what happened or that such a thing went wrong today or something like that, which is very good. Sam and I would talk when we have the opportunity, such as when kids are in bed for the night, or when doing dishes, and so on.

I usually set a goal and stick to it. But always try... to use a reasonable approach. Not always a confrontation.

I like to keep the structured play over at the day care. At home I like to have the natural normal environment of learning, like getting dressed... And things like "Put your arm through" letting things happen, naturally. We're all trying to do that. The three of us let Shane do it. Or we try to remind each other to show him how to do things and help him become more independent.

I am very optimistic. I know things will work out. It's just... you just have to be patient sometimes and trust in God. Phillip lets things bother him a lot. I try to help with those things. He worries a lot about finances and things like that. I don't. I used to worry a lot and I just found that worrying did no good. Worrying didn't work things out. They're going to be there anyway whether you get sick and have ulcers or whether you have a good day. I take one day at a time instead of living week to week.

The first thing we had to do was to get him a little bit of time in a regular classroom so that kids could meet him. Regular kids could just meet him and make a choice to see if they would like to become part of the Circle with him. It took us until about May of the following year before we could convince the school that Bruce had a right to be in a regular classroom. Just a home-room, that's all we wanted - five minutes of home-room to start.

The education collective of which I am a member... It's a group... It's made up of parents of children from all the different disability groups... We just look at all issues around education and that sort of thing. It's kind of falling apart. At one time it did provide a bit of support but it was mostly a working kind of coalition to try to effect change. It was very busy looking at legislative things and policy stuff. But one of the things we have been doing for five years is running this summer program to try to maintain the kids skills... It's a parent-based program. Parents must enter their children into the program. Parents must decide on what the program will be... if they choose not to (involve teachers, school systems, whatever), that's O.K. too. The only thing that this program insists on is that parents are involved in setting up programs and determining priorities for kids. Every child who enters the program gets one-one-one tutoring. There's no grouping of kids, there's none of that... The parents volunteer to raise the money to come up with the program each year... So we (the parents of kids with disabilities) raised the money and we hired university students. We give them three weeks of training. We train them in different disabilities. We assign them a caseload of kids and some people might have two kids on their caseload. No child can have more than four hours a day of this program.

5. Growth

Like all families, these families have experienced growth and insights about themselves as individuals and as families. All three families point to their daily encounters with disabilities as opportunities for growth.

Quotes # 17

For a while we experienced an awful lot of shock when Bruce first developed friends. There was a lot of not really believing or trusting. Because you'd go to these "Circle Meetings" with these kids and they would say these wild and wonderful creative things. They got a real good picture of Bruce's life, first of all. Mary went through a whole thing about who Bruce was and what life was like for Bruce, and drew some comparisons, she got the kids to look at: If their life looked like Bruce's how would they feel? And would Bruce feel any differently? Well they certainly didn't feel that he'd be feeling any differently, that he's probably pretty miserable and wishes things were different. So they were a perceptive bunch of kids as all kids, I think, are... probably more perceptive than most adults.

They started out being very focused around the school. They'd take him out at lunch or hang around with him after school, or "Maybe he could come to my house for a visit after school if you guys would pick him up?" Little steps like that started to happen. I remember after that started to take place, there was a bit of a non-belief or a lack of trust, on our part, that this was going to last.

I really don't... I don't have too many regrets in what I had to do over the years. Sometimes I had to compromise in one area to get more in another area. When you look back there were no other options open to you... I look at times that were taken away from the boys because I was tied up with her being sick or things like that. But there was no other way that it could be done... Because the need was great that was there at the time.

I don't think that anxiety about time away from the boys every goes away. You certainly reflect back on that. And even the fact that it still happens to the present day.

When she (Margaret) went to play school, she was very protective of him. And she had to sit by him all the time and things like that. I tried to explain to her: Shane has a lady that works with him at the day care... She has a non-verbal son herself. The lady has all the signs and she's excellent. It's just excellent. And Margaret's becoming more comfortable with giving up the responsibility to her. So now Margaret... she doesn't have to sit beside Shane. It's like all those things are leaving her. So I think by the time she hits school age she will be able to.. I hope to put them into different classrooms. And I hope she won't mind. So that she doesn't have to feel that responsibility.

No I don't get overwhelmed. Thank heavens for that. No. I don't think I overwhelm too easily... I do have a sense of humor. Cause there are days that you might as well laugh than cry... I do have a sense of humor. I can see that... I quite readily say when I've had enough.

It was hard on them I think... definitely. I think when you look back at those days, there had to be a certain amount that they (Marianne's brother's) lost. Yes. There's no denying that. But they are none the worse for the experience. I would take the oldest fella, thirteen now, and compare him to other thirteen year old's, that we know. I just look at the sense of responsibility that he has compared to other kids, and their general attitude to somebody with a disability or somebody that's a little bit different. Our sons, they seem to have that extra thing that perhaps you wouldn't see in other teenagers that are so self-centered. Now I'm not saying mine are the best, they can be either. There are times when they get pretty darn mad at Marianne. You know there's no doubt about that. But over all, I would say they lost but they gained a lot too. I think that they've gained from the experience, as well.

So all in all it would be nice to have something like that (parent support group). I realize that the most important thing is realizing that you don't have to do it all... Just because your child has a disability it doesn't mean you have to provide everything for your child. If I was going to look at it that way, I probably wouldn't be able to cope, because no one person can take that much responsibility and be able to remain sane and well balanced and healthy.. You're going to become insane, if you don't get the support that you need to make things work. I can't provide everything.

Doug (Bruce's older brother) has started to see Bruce very differently. We were over when they just moved into their new place. He invited us over to see their place, so the three of us went over and Doug said, "Bruce is really doing great isn't he?" He (Doug) is starting to notice.

I think all in all, it's been a positive thing, but there's no doubt that they had to give all in some areas to gain in others... There's no doubt about that. It's not all a bed of roses. But I think ultimately what we've gained from these experiences, it's going to help them.

I've heard various people comment, teachers of the boys or something like that. Something, somewhere has made a big difference in them... If there's somebody hurt in a fight, if somebody has a problem, it seems to be our fellows, not just ours but others too. But they principally go and handle the situation.. And they look out for those that are being teased on the playground or something like that.

Oh yes. He's very good with Marianne. He's always been very supportive of her and things like that. Perhaps it has taken him a little longer to adjust to the fact of a child with a disability. But I think that happens everywhere... I had those five additional days in hospital, too, where I was exposed to her and was the care-giver to her. So I always had five days plus on him.

I don't take responsibility for Phillip anymore. I think that the more and more that I slacken off in responsibility, the more that he looks at himself. He has to look at what's causing his problems. I try not to let his problems affect us as a family and make him feel guilty... It took a lot of struggle and a lot of realizing.

I don't let things bother me because I've made up my mind that things are going to work out. Things will get better and that it's just a matter of slowing down and not getting in too much of a rush. The answers will come. You can get frustrated but talk about it and you have to let people know what's happening with you, even if it's not good. If it's really bad you still have to let it out instead of keeping it in. I need to talk out my feelings.

I guess my conviction. It would have to be that. I just so believe. And just my love for Bruce and... Well I think the same holds true. I think just our ability to support one another, it helps to build on your own inner strengths and your partner's.

6. Parents and Professionals

During the course of our discussions, each mother articulated some ideas of how the relationships between parents and professionals could be improved.

Quotes # 18

I think definitely the professionals... sometimes maybe they are thinking that the parents are looking for somebody to put the blame on, or something. Maybe they think that's why we are hard on the professionals; but I don't think that's where the majority of us are coming from. Really what we're trying to get across to them more, is just try and see the child as a whole. Just not this child that this mother or father has to deal with. There are others involved. There's only a certain amount of time that you can do it. And most parents, 99.9% are doing the best job they can anyway, or the child would never have even shown up for the appointment... They're doing the very best they can. And I don't think there are too many people that are slack in the sense that if you want your child to accomplish to the very best he/she can. You're going to darn well work and put some effort into it. You're not going to let the child sit in front of the T.V. and all this. And I think the professionals do have to realize that. They have to realize that you have to work with the parents. Don't work against them or nothing, nothing will work out... nothing at all, actually.

We've had a lot of it confirmed by people at the J.B. Children's Hospital that chances are if we don't know it, they don't know it either. Now, of course, obviously they've got some medical training that we certainly don't have. But just in terms of Bruce as a person and what's really happening there... I would seriously question if Bruce would be here today if it were not for our ability to act on his behalf, to know what's going on with him... For others it (parental involvement) is just lip service. It's on paper. They believe it, parents are important. If you never show up for a parent interview you're labelled too. But if you do and you try to get involved uh, there's sort of a line. Like get involved but only this far.

By doing this (taking part in this research project). Maybe the professionals will look at us in a different manner. I was explaining that to Phillip last night, how easy it is for professionals to forget that there is a family. That it's not just the Mom and the child, it's the Mom and the Dad and... And there's the brothers and sisters and the grandmothers and the grandfathers. It's the whole family and all the people that, the person is tied to... They all affect the child's life.

It hasn't been a stressful situation with my pediatrician. but any of the other disciplines I have had a lot of stress... It's the attitude they exhibit. And mind you, you can't put everybody in one lump sum in that. But there's some in the same discipline but have a different approach... that makes it easier for you. But generally speaking I would have to say it is the attitude. And absolutely no comprehension or willingness to acquire knowledge of what it is to have the child for twenty four hours a day, and try and keep a normal family circle going. They can come up with umpteen suggestions that are not practical to implement at all...

I get really stressed-out with some professionals who are hell-bent that the child should acquire a certain skill at a certain age, and if not accomplished, would give the impression that the parents were not teaching it or even working on it. They did not consider if it was the approach being used by themselves or, if indeed, the child needed the skill at this time. Does it make sense to the child?

She has different attitudes but yet the same discipline of speech and language pathology, (she has) a different way and a much different way of working with Marianne.

They don't understand. "Well, this is what we have for you in the way of services." "Well we don't need any of that, I need all the stuff that you don't have..." Cause they've just got stuff for people, say, who can't afford certain things. But that's never really been our issue. At least not lately. When we were first together it was an issue. Now it's not really an issue. We need the stuff that people think, gee that's not the service we give. You get that from your family or you get that from...

Don't provide parents with a list of do's and don'ts. Ask them "Do you think that's possible that you can do that certain task and without putting added stress on yourself? Would you have time to implement that? And let me know how you're getting along with it, you know. If it's useless, call me up and tell me it's useless. If it's something that's going to work for you, great. Let's develop on it." That type of thing. But they never did seem to have that kind of approach. I didn't see it, anyway, with the people that I had dealt with.

The basic philosophy I've always had with these professionals is I watch first, their reaction to her. Then I could find a base from there; where we're going to go, whether it's going to be a success or failure. And so far, I've been pretty well "on". If the professional person, (as I arrive with Marianne) is "How are you Anne?" and everything like that and there has been absolutely no mention whatsoever of Marianne being there or looking at her or anything like that. Well, that to me, says it's just not going to work out. If they acknowledge her and make her feel the least bit welcome... Because she knows who's friendly with her and who isn't.

Well I found with that program it was just me and Shane going to the course and if it would have been somebody coming into our home and showing us how it would work, in our home... I think there needs to be more of how you can use the family strengths... the things that are in the family.

You need to bring everybody together because people feel left out. It's hard to do once you learn a new technique and once you do it, then it's hard to teach that other person or bring him in. Like with my husband: Because he wasn't physically able to be there when Shane was diagnosed or at the hospital and stuff like that, it makes it extremely difficult to draw him in. It's just so hard once you get into a pattern of doing things with your child and taking responsibility. It's hard, then, to go and say, "Here could you do this?"

7. Satisfactions

Martha, Anne, and Sara, while freely discussing the stresses, anxieties, demands, and complications of family life when one child in the family is disabled, also indicate in many ways, the satisfactions that family members have experienced as a result of each family's challenge. I present only a few specific comments in this regard. More striking than any individual comment, however, is the air of confidence and competence that these mothers present. Yes, they get tired; yes, they have had to make specific adaptations, in varying degrees; yes, they have faced many struggles, which are not over. Nevertheless, each mother can express satisfaction concerning her experience.

Quotes #19

We'll just go sit on the deck and David will read his book and I'll read my book or work with the plants. We also, believe it or not, have fun with Bruce... We get down on the floor and we start to play with him. That's fun. I like that.

I had no choice, But, no, I know I could never think that the burden was too much, even when she was so desperately sick. Those were hard times. Oh they were rough... nights and nights and nights of lost sleep. And you'd come home and you'd wonder what could I get for supper? The other ones are crying in your ear looking for something to eat. It was rough going, there's no doubt about it. But no, I'd never ever tell anybody the burden's too great. You know, it took this two and a half years of physio, but when she took that first step on her own... It makes a difference, makes a big difference, ya.

Something that really makes me feel great is things like on the week-end you get to "sleep-in" in the mornings, and the kids will come into the bedroom. We'll all be piled up on the bed and they'll be giggling and laughing and rolling around. That's when our family is the closest... We all snuggle up in our bed and that really makes things special. And then Sunday mornings I take the children to Sunday School and I like doing that, too. I like being with them.

If there is just David and Bruce here at home or just Bruce and I here at home he is a little more subdued. When all three of us get home from work and school (lately they have been home before me) when we are all home together, there is an instant change in Bruce. All of a sudden he is more lively, happier. He is clapping and laughing and carrying on and he seems to like the time around supper when everybody comes home. It is a good time for Bruce. He really enjoys that.

I hope I see that (less societal ignorance about disabilities) in my life-time, I really do. Because, that is our main basis for... Our main philosophy behind integration, is that these other children will say when they are grown up and out into the work force, "I grew up with someone who had Down Syndrome and things are not as bad as what you are trying to make them out to be."

QUESTIONNAIRE DATA

Family #1

David and Martha completed the questionnaires independently and made them available for me to collect on Friday night of our first week of study. They had some difficulty with the Profile of Family Needs and Social Support, and the Personal Network Matrix. Consequently, I elected to simply deal with these scales through conversation together, at the point of our family discussion. I made this same change when meeting with each of the other two families of this study.

In general, this couple shows a very high amount of agreement and compatibility in their thinking. There are some minor differences of opinion but sources of stress and sources of support are identifiable from the data. As well, information from these questionnaires support the information already provided by Martha through interview. Responses have been graphed or put into table form. These can be found in Appendix D and Appendix E, respectively..

1. Family Functioning Style Scale: (Table 1)

This scale examines in what manner a family functions and what it's members see as the family's strengths. Martha and David were never more than one value point apart when responding to these scale items. On 14 of the 26 items (54%) they gave exactly the same response. They were within one value point of agreement on all other responses (46%) and present a profile of a loving, caring, couple with a positive outlook on life, who solve family problems independently, primarily by supporting each other. When asked to list family strengths, 5 out of 8 of David's items were like Martha's and 5 out of 10 of Martha's items were like David's. They listed inportant family strengths as "loving and caring"; "open communication"; "sharing responsibility"; "flexibility"; "being committed to making things work"; "supporting each other"; "taking time for one another"; "working hard"; "sharing similar dreams"; "We don't fight and argue"; "we share concerns over how individual decisions will impact on others in the family".

Martha and David together indicated in 83% of their responses that the characteristic listed on the scale was "sometimes" or "often" like their family. These response indications are about evenly split for this couple with Martha giving 21 such responses and David giving 22.

2. Family Needs Scale: (Table 2).

This scale tries to delineate specific needs of the family. It presented some problems for David. He answered only 10 of 41 items, indicting that the others (a little more than 75%) were "NA" (non-applicable). Martha indicated only 8 out of 41 items (less than 20%) as "NA". During our discussion David explained that their family wouldn't have to go outside the family to solve the problems of the needs presented by the items. They wouldn't require help or assistance. For the ten items answered by both parents, 5 responses (50%) were the same or within one value point. Martha and David were two or more value points apart on the remaining five items:

#13 adapting my house for my child
#19 transporting my child
#33 finding a school placement for my child
#35 having time to take my child to appointments
#36 exploring future educational options for my child.

In every case, except #19, these needs were more pressing for Martha than for David. Both parents indicated #29 (caring for my child during work hours) as an area of high need (needing help "almost always"). As well, Martha indicated #16 (planning for future job of my child) and #33 and #35 (see above) as high needs.

Martha and David together indicated in 65% of their total responses that they "sometimes", "often", or "almost always" have the need articulated by the questionnaire statement. Martha indicated these needs more often (21 responses) than did David (7 responses).

3. Family Resource Scale: (Table 3)

This scale tries to determine whether or not a family has adequate resources of time, energy, and money. It's focus is on the family as a whole, as well as individual members. David answered only 8 of 31 items (26%), indicating 23 as "NA". Martha answered 22 of 31 items (54%). Of the eight items that both answered, all responses were within one value point. All of David's responses indicated "usually" or "almost always" adequate resources. Fifteen of Martha's responses indicated "usually" or "almost always" adequate resources, but seven (32% of her responses) indicated resources as only "sometimes adequate":

#12 time to get enough sleep/rest
#14 time to be by yourself
#18 time to be with close friends
#25 time to socialize
#26 time to keep in shape and look nice
#30 money to save
#31 time and money for travel/vacation.

David indicated "NA" to numbers 12, 14, and 26. These differences show differences in personal demands and need and probably reflect, as well, the greater demands on Martha to assume responsibility for the daily management of the home and care of their child.

4. Family Support Scale: (Table 4).

This scale tries to delineate sources of support for the family. David and Martha show considerable agreement on this instrument. David answered 10 of 20 items (50%) and Martha answered 14 of 20 items (70%). Of the nine items that both answered, they gave the same response or were within one value point on seven of the items (78%). It should be noted that for both Martha and David, 17 of 24 total responses (71%) were answered "sometimes" or "not at all" helpful. Martha indicated this lack of support more often (10 responses) than did David (7 responses). Only one item was answered as "extremely" helpful, by both parents. This item was "spouse" (#5). Item #14 ("My family or child's physician") was answered "extremely" helpful by David, while Martha indicated a point halfway between "very" and "extremely" helpful for this item. (Here they are indicating the support that they received from the specialist in Regional Centre, not from their Capital City physician.)

They gave responses more than one value point apart on two items:

#1 my parents (Martha 3, David 1)

#2 my spouse or partner's parents. (Martha 1, David 3).

In this case, their "divergent" responses indicate agreement that Martha's parents are "generally helpful" and David's parents are "not at all helpful".

5. Personal Network Matrix: (Tables 5 and 6).

This scale tries to delineate people or groups with whom each parent had made contact in the previous month and the perceived level of their support. David and Martha completed parts A and C of the scale.

For part A each indicate a fair amount of contact with persons outside the home during the previous month. Martha responded to 20 items and David responded to 21 items. Martha indicated slightly more frequent and different contact with people outside the home than did David. Ninety-four percent of their responses were the same or within one value point. Martha responded to the open-ended questions by writing in "The Society" and "private business".

Those items indicating frequent contact (ten or more in the past month) by either Martha or David are as follows:

# 1 spouse or partner
2 my children (i.e. Bruce)
3 my parents
4 spouse or partner's parents
8 friends
12 co-workers
# 13 baby sitter
14 day care or school
20 social service department
# 23 private business (providing special equipment)

Data from part C of this scale show, however, that not very many of these contacts outside the home are viewed by either Martha or David as being dependably supportive. Three items were marked by both partners as dependably supportive "all" or "most of the time":

# 1 my spouse
# 13 babysitter

# 16 child/family doctor (meaning the specialist in Regional Centre)

In addition, David indicated that he feels the hospital (in Regional Centre) and Social Services are dependable "all of the time" and "most of the time", respectively. Every other possible source of support (17 options) was regarded by at least one partner as only "occasionally", "sometimes", or "not at all" supportive. They responded the same or within one value point on six of the ten items (60%) addressed by both parents. Responses to two items were more than one value point apart:

# 14 day care of school

# 18 hospital/special clinics

In both cases David perceived more support than did Martha. In general, David seems to feel more support outside of the home than does Martha. One item (#23, an open ended option) received no response from either parent.

6. Inventory of Social Support: (Table 7).

This scale and its matrix attempt to delineate people or groups in the lives of respondents who supply help or assistance, when asked. David responded to 18 of 20 items (90%) as did Martha. Together they responded to 16 of the same items and all of these responses (100%) were the same or within one value point. To the two items that Martha responded with "not applicable" (#10 church members and #11 minister, priest of rabbi) David responded "not at all". To the two items that David left blank (#19 and #20), both write-in opportunities, Martha wrote "The Society" and the private business which had recently provided some special equipment for their home.

Both David and Martha indicated contact with "spouse", "my children" (meaning Bruce), "co-workers", "baby sitter, day care, or school" as representing the majority of their contacts during the past month (August). These persons also received the most "checks" on the matrix, indicating perceived sources of help or assistance for the twelve specific instances of need defined by the authors of the matrix. In addition, Martha indicates "friends" and "Bruce's friends" as sources of help or assistance. Martha made 46 "checks" on her matrix and David made 31. Ten (22%) of Martha's are under the heading of "spouse". For David, eleven (36%) are under the heading of "spouse". Each is a big source of help and support for the other. David's source of support is more focused on Martha, whereas Martha sees a few more possibilities of support. Both find Bruce well accepted by the possible sources of support as defined on the matrix by its authors.

7. Support Functions Scale: (Table 8)

This instrument tries to find how much help and assistance respondents need in each of twenty different areas. David answered 15 of 20 items (75%) and Martha answered all items. Of the items answered by both respondents, answers were the same or within one value point for 9 of 15 items (60%). Martha's and

David's responses were more than one value point apart on six possible personal needs:

- # 4 someone to talk to about problems with raising your child
- # 7 someone to fix things around the house
- # 8 someone to talk to who has had similar experiences
- # 10 someone whom you can depend on
- # 13 someone who accepts your child regardless of how he acts
- # 14 someone to relax or joke with.

For items 4,7,and 8, Martha expressed greater need. For items 10, 13, and 14, David expressed greater need. Notice that David's indicating an expression of need for Bruce's acceptance is inconsistent with David's response (on the Inventory of Social Support) that Bruce is well accepted by all persons or groups listed on the matrix. I don't know how to explain this.

Together, David and Martha provided 35 responses to this scale. Seven of these (20%) indicated the need for help or assistance "often" or "quite often":

- # 3 someone to care for your child on a regular basis (Martha and David)
- # 4 someone to talk to about problems with raising your child (Martha)
- # 9 someone to do things with your child (David)
- # 10 someone whom you can depend on (David)

# 13 someone who accepts your child regardless of how he acts (David)

# 14 someone to relax and joke with (David)

Notive that David expressed more of these needs than did Martha.

8. The Matrices of Scales 2 and 6

The evening was getting late, by the time we attended to the matrices of these two scales. One scale refers to family needs (#2), the other to personal needs (#6). While David had been most cooperative throughout all of the discussion and in responding to the questionnaires, I felt that he had clearly indicated that he didn't want to talk too much about his personal needs. Because of this, and because of the late hour, I ignored the sixth scale and focused instead on the second scale. Martha had listed several "projects" on both scales 2 and 6. I appropriated three of her more family oriented "projects" (less personally oriented) and we brainstormed sources of support for accomplishing these "projects". The items are called "projects" because they require time and energy to accomplish. Martha's "projects" are as follows:

a. Childcare (employment related)

b. "Circle of Friends"

c. Vacations

In the first instance, we discussed who might be a source of help in planning for Bruce for some kind of employment related care for Bruce. Possible sources included Bruce's current caregiver

(Collette) who looks after Bruce while his parents are at work and when Bruce is not in school; Health and Social Services; Vocational Services; the technical school; and small businesses in the community. We stipulated that we wanted work for Bruce that he would enjoy and that was integrated into the community.

In the second instance, we discussed who might help to breath life into Bruce's already existing "Circle of Friends". The friends are willing and are helpful. The problem is finding ways that Bruce can see them in school on a daily basis, and then supporting the enlargement of that contact as his friends involve him in their lives (as they had when they were all in junior high school). Our discussion recognized that there may very well be both qualitative and quantitative differences now as compared to when Bruce and his "Circle of Friends" were in junior high school; but all see the daily contact in school as a necessary beginning to invigorating this group. It was decided that people who could possibly help on this project were Mary Winston and Gary Marriott, both co-workers of Martha's. Each has either been involved in this project before (Mary initiated it.) or currently has good contact with the school (Gary). Other possible sources of help include the school and Bruce's current teacher(s). We decided that Bruce also needs a place to go where he can meet more friends because, as with all people, friends sometimes exit from our lives. We also noted that people who might be Bruce's friend need an activity to do with Bruce.

Lastly, we discussed people who could help when this family or this couple wants to take a brief holiday. David stated that they hoped for respite care that would have something interesting in it for Bruce. In other words, they want more than simply a place to "park" Bruce while they take a holiday. They stated, as well, that they also needed care for Bruce for the two weeks immediately before the start of school each year. The discussion eventually turned into a brainstorming session to find ways to expand the base of support for this family, in general. Collette's name was mentioned again and it was acknowledged by both David and Martha that they would be "sunk" if something happened to Collette or if she couldn't take Bruce anymore. They discussed another family who had expressed a willingness to look after Bruce for short periods of time. Other possibilities included retired people (a couple?) and students.

David raised some concern about continuity and a need to plan with an eye to what these caregivers mean to Bruce from Bruce's point of view. It was decided that the university students would be better than the technical school students solely because they would be "around" for a longer period of time.

Summary

Our discussion including the MAPS planning and examination of the questionnaire data lasted about three hours. Everyone who was present took part and offered ideas and opinions. The questionnaire data confirms information that Martha had already provided through interviews. Both the interview information and the questionnaire data indicate a closely knit, supportive family with many current and future educational and quality of life concerns about their son. In general, Martha indicated more demands on her and more needs than did David; though David indicated some areas of isolation and need. While this couple provides good support to each other, they do not feel much support from others outside of themselves. A few friends and a few professionals who have provided support despite a "system" which is largely disinterested, are really all that they can delineate as sources of support after more than a decade of joint concern for Bruce.

Family # 2

Anne and Sam completed the questionnaires independently and had them available for me by noon of the first week of study. In general, this couple indicates a high level of agreement and compatibility in their thinking about their family. There are some minor differences, often reflective of their different family roles. They have one more serious difference in that they seem to perceive support from extended family members at different levels. Anne, who carries a large part of the daily care of their children perceives extended family support as somewhat less than Sam perceives it (more about this below). Both find each other very supportive and both find their sons very supportive. As well, information from these questionnaires support the information already provided by Anne through interview. Responses have been graphed or put into table form. These can be found in Appendix A and E, respectively.

1. Family Functioning Style Scale: (Table 1)

This scale examines in what manner a family functions and what it's members see as the family's strengths. Data from this questionnaire indicate that Anne and Sam are in considerable agreement about how their family functions and what constitutes the family's strengths. They gave the same responses for 11 of the 26 items (42%) and 14 other responses were within one value point for each partner (54%). They gave responses more than one value point apart for one question (#5). ("We are able to share our concerns and feelings in productive ways") Anne answered "3" ("generally like my family") while Sam answered "1" ("a little like my family") indicating slightly different experiences of style of family functioning. In general, Anne and Sam present themselves as a loving, caring couple with a positive outlook on life who are pretty self-sufficient in solving their problems. They solve their problems primarily by supporting each other. They also gain support from their sons. When asked to independently list family strengths, three of Sam's responses were like Anne's ("help with day to day chores", "take time to talk to one another about their days", "spending quality time with the children either at home or at their sports activities"). Each wrote an additional strength: "...spell one another off...to see that the spouse gets a well deserved break." (Anne); "... help each other to help Marianne..." (Sam).

Sam and Anne together indicated in 62% of their responses that the characteristic listed on the scale was "sometimes" or "often" like their family. These response indications are found more often for Anne (20) than for Sam (12).

2. Family Needs Scale: (Table 2)

This scale tries to delineate specific needs of the family. Sam indicated that 17 of the 41 items (42%) and Anne indicated that 11 of 41 items (27%) were "non-applicable". Where both answered, 16 of 22 responses (73%) were the same or within one value point. This means that when they both responded to an item, they were in agreement or closely agreed for 73% of the responses. For six of the items, they responded more than one value point apart. In each case, Anne indicated a higher need, probably as a result of her family role:

21 finding someone to talk to about my child
29 caring for my child during work hours
30 having emergency child care
32 finding care for my child in the future
35 having time to take my child to appointments
36 exploring future educational options for my child.

Anne responded to 8 items which Sam marked "non- applicable", probably indicating her own personal needs and responsibilities (none indicated areas of high need):

# 6 having food for three meals for my family

# 7 having time to cook healthy meals for my family

12 completing chores, repairs, home improvements

14 getting a job

15 having a satisfying job

24 having time to take care of myself

26 finding special dental and medical care for my child

27 planning for future health needs.

Sam answered two items which were marked "non-applicable" by Anne. He indicated that these were "seldom" problems:

17 getting where I need to go

20 having special equipment.

Anne and Sam both indicated that "often" they have a need to save money for the future (#4). Anne indicated, as well seven other items in which she "often" feels a need:

4 finding someone to talk to about my child

29 caring for my child during working hours

30 having emergency child care

31 getting respite care for my child

32 finding care for my child in the future

36 exploring future educational options for my child

41 travelling/vacationing with my child

Anne and Sam together indicated in 52% of their total responses that they "sometimes", "often" or "almost always" have the need indicated by the questionnaire statement. Anne indicated these needs more often (22 responses) than did Sam (6 responses).

3. Family Resource Scale: (Table 3)

This scale tries to determine whether or not a family has adequate resources of time, energy, and money. It's focus is on the family as a whole, as well as on individual members. Sam indicated 2 of 31 items (3%) and Anne indicated 3 of 31 items (7%) as "non-applicable". Where both answered, no responses were more than one value point apart, indicating considerable agreement.

From this scale, we can see that Anne and Sam have four items for which both have indicated resources are only "sometimes" adequate or "seldom" adequate:

# 20 babysitting for your child/children
# 28 money to buy things for yourself
# 30 money to save
# 31 time and money for travel/vacation

Anne has indicated three additional items which are only "sometimes" adequate:

# 8 good job for yourself or spouse/partner (here referring to herself)
# 15 time for family to be together
# 18 time to be with close friends.

Each has indicated one additional item as only "sometimes" adequate:

# 25 time to socialize (Sam)
# 29 money for family entertainment (Anne)

The responses show us that both Anne and Sam feel there are some personal and family needs that are not being met. Together, Anne and Sam indicated in 22% of their total responses that resources articulated by the questionnaire statement are "seldom" or only "sometimes" adequate. Anne indicated these more often (8 responses) than did Sam (5 responses).

4. Family Support Scale: (Table 4)

This scale tries to delineate sources of support for the family. It is the one scale where Anne and Sam show clear differences of perception. They agreed or were within one value point in their responses to 11 of the 16 items that both answered (69%), but they were more than one value point apart on 5 of 16 of the items (31%). They don't agree on the value of parent's and spouses parent's support (items 1 and 2). They don't agree on the value of early intervention in day care or school support (items 15 and 16). They have different amounts or valuing of support from their friends (item 6). These differences were discussed during a family interview and what looks like rather dramatically different perceptions of support can be explained by different interpretations of the scale items and/or different family responsibilities. It should be noted that between the two sets of responses, one or the other of these parents indicated 17 of 34 total responses (53%) as "sometimes" helpful or "not at all" helpful. Only two items were marked "extremely" helpful or "very" helpful by both partners:

# 5 spouse or partner

# 14 my family or child's physician.

Except for items #15 (early childhood intervention program) and #16 (school/day care center) which Anne categorized "extremely" helpful, Sam feels more supported than Anne.

5. Personal Network Matrix: (Tables 5 and 6)

This scale tries to delineate people or groups with whom each parent had made contact in the previous month and the perceived level of their support. Anne and Sam completed Parts A and C of this scale.

For Part A, each indicated a fair amount of contact with persons outside the home during the previous month. Anne responded to 20 of the items and Sam responded to 21 items. Both indicated about the same frequency and kind of contacts. Where both answered, 16 of 20 responses (80%) were the same, or within one value point. Four responses (20%) were more than one value point apart.

# 3 my parents

# 8 friends

# 12 co-workers

# 18 hospital/special clinics

Sam sees his parents more often than Anne sees hers because Sam's parents live close by. Sam sees fewer friends but sees more co-workers. Anne is currently unemployed outside of the home and sees more friends and no co-workers. Anne goes to more "appointments".

Those items indicating frequent contact (ten or more in the past month) by either Anne or Sam are as follows:

# 1 spouse or partner
2 my children
3 my parents (i.e.Sam's)
# 8 friends
9 neighbors
11 minister, priest or rabbi
12 co-workers (i.e. Sam's)
18 hospital, special clinics

In part C, Anne responded to twenty items and Sam responded to 21 items. Each left the two open-ended questions blank. Their responses were the same or within one value point of each other for 16 of 20 items (80%). They were two value points apart for 4 of 20 items (20%). In these, Sam found the first three listed items more dependable, whereas Anne found the last listed item more dependable:

# 5 my sister/brother
# 8 friends
# 10 church members
# 14 day care or school.

Neither Anne nor Sam indicated anyone that they could depend on "all of the time". Both indicated that each could depend on the other "most of the time" (# 1) and Anne indicated that she could depend on her children (#2) and the school (#14) "most of the time. Sam indicated that he could depend on his parents (#3); Anne's parents(#4); his sister/brother (#5); and his friends (#8) "most of the time". Sam definitely feels more support outside the home than does Anne.

6. Inventory of Social Support: (Table 7)

This scale and its matrix attempt to delineate people or groups in the lives of respondents who supply help or assistance, when asked. Sam responded to 18 of 20 items (90%) and Anne responded to 17 of 20 items (85%). Both ignored the open-ended items at the end of the scale, and Sam indicated "other agencies" (item #18) as "not at all helpful". Anne ignored this item. Where both responded, 14 of 17 responses (82%) were either identical or were within one value point. Three responses of 17 (18%) were more than one value point apart; but probably reflect each partners family roles more than any difference of perception or opinion. (Sam sees more co-workers; Anne sees more school personnel; Anne attends more medical appointments.)

Together they have frequent contact with a fair number of people beyond their immediate family. Anne indicates seeing friends (#8); neighbors (#9); school personnel (#12) and child/family doctors (#14) at least ten times in the previous month. Sam indicates seeing church members/minister (#10) and co-workers #(11) at least ten times in the previous month. This seems to indicate a bit of scarcity of informal and "fun-generating" contacts for Sam outside the home.

Anne made a total of 33 "checks" on her matrix and Sam made a total of 23. Data from the matrix indicate that for Anne, the greatest sources of support are Sam (8 checks), her children (5 checks) and her friends (5 checks). Sam's greatest sources of support are Anne (11 checks), his parents (4 checks), and himself (4 checks). Eight (24%) of Anne's matrix checks are under the heading of "spouse). For Sam, 11 (48%) of his matrix checks are under the heading of "spouse". Each is a big source of support for the other. Sam's source of support is more focused on Anne, whereas Anne sees a few more possibilities of support. Both see Marianne's acceptance much more narrowly defined to close family members and friends.

7. Support Functions Scale: (Table 8)

This instrument tries to find how much help and assistance respondents need in each of twenty different areas. Anne and Sam responded to all items. Their responses were identical or within one value point for 18 of 20 items (90%). They were two value points apart on 2 of 20 items (10%). In both cases Anne indicated more need:

# 8 someone to talk to who has had similar experiences

# 20 someone who tells you about services for your child or family.

These probably reflect Anne's family responsibilities and a certain level of isolation, at least as far as the factors associated with their child's disability is concerned. This is further supported by the five items in which Anne indicated that she "often" feels the need of help or assistance:

# 5 someone to help you get services for your child
# 8 someone to talk to who has had similar experiences.
# 13 someone to accept your child, regardless of how (s)he acts
# 17 someone to care for your child in emergencies or when you must go out
# 20 someone who tells you about services for your child or family.

Of the 40 total responses made by this couple to this questionnaire, five (13%) indicated a need "often". All of these responses were Anne's.

8. The Matrices of Scales 2 and 6

An informal discussion addressed these matrices during our family discussion. The content of the scales were combined and we focused on concrete areas of need and concrete areas of support. We addressed three "projects" from those listed by Anne and Sam on their individual questionnaires. "Projects" are things that need to be done concerning the disabled child and which require the investment of time and energy. Anne's and Sam's "projects are as follows:

-computer time

-speech/alternate communication

-making new friends/recreation.

Sources of support and resources already identified by Marianne's parents, were also listed:

-school/school board

-teacher

-speech therapist

-other parents (of disabled kids)

-other parents (of able kids)

-other children

-the Society (provincial)

-the Society (local).

Anne and Sam were then asked to brainstorm additional possible sources of support and additional possible resources. They added two additional possible sources of support:

-other community agencies or groups (e.g. Brownies/Guides)

-church.

This discussion served to focus Anne's and Sam's thinking and to help to generate ideas for broadening the base of support for this family.

Summary

The questionnaire data confirm the information that Anne had already provided through interviews. In general, this couple provides good support for each other, and their sons provide good support and balance in their home. Nevertheless, they feel pretty isolated. Anne, on whom a large part of the daily responsibility for all the family's functioning falls, feels particularly isolated and frustrated. Sam provides good support; but he has family responsibilities which take him outside the home and away from much of the daily direction of the home. Anne seems to have adequate social support outside the home (friends and neighbors). Sam's social support outside the home (co-workers and church members) might be more serious and less stress-reducing than Anne's. It is Anne who carries on most of the required contact with the schools, the speech therapist, the medical profession, and any other professionals with whom this family needs to interact. This is a source of stress and isolation for Anne, and a source of frustration for both parents. They see themselves in charge of their lives and in control of their situation. They also see themselves as a unit of five, pretty much alone in their struggle to provide optimal developmental opportunities for their children, especially their disabled child.

Family # 3

Sara and Phillip completed their questionnaires independently and gave them to me when we met for the MAPS planning session. Neither parent expressed any difficulty over any of the forms. They both responded to almost all items on most scales. When items were ignored, often this was done by

Phillip. In general, this couple shows much agreement in their thinking and what they are experiencing in the parenting of their children. There are some interesting differences, however; but sources of stress and sources of support are identifiable from the data. As well, information from these questionnaires support the information already provided by Sara through interview. Responses have been graphed or put into table form. These can be found in Appendix D and Appendix E, respectively.

1. Family Functioning Style Scale: (Table 1)

This scale examines in what manner a family functions and what it's members see as the family's strengths. Both Phillip and Sara answered all 26 items. For 10 of the 26 items (39%) the responses were identical and for another 10 items the responses were within one value point (39%). For six of the items (23%) responses were further apart than one value point. In all but item #7 of these, Phillip found the item option more like their family than did Sara:

# 3 We believe that something good comes out of the worst situations.

7 We generally ask for help from persons outside our family if we cannot do things ourselves.

9 In our family we are always ready to "pitch in" and help one another.

# 11 No matter what happens in our family, we try to look "at the brighter side of things".

16 We enjoy time together even if it is just doing household chores.

21 We generally talk about the different ways we deal with problems of concerns.

When asked to list family strengths, Sara listed eleven and Phillip listed seven: "share medication giving"; "share responsibilities for household chores"; "share teaching of self help skills"; "give lots of love and reinforcement"; "allow family members to make mistakes"; "give each other free time to ourselves"; "allow each person to pursue interests"; "rely on one another to help decide major issues"; "share financial issues (maintain income for family)"; "provide for education for each family member"; "support each other when a decision has been made"; "able to deal with problems (financial, family)"; "do things together (housework, getting kids to school, bathing kids, dressing kids, Shane's medicine, doctors appointments)". Phillip's list presented more elaborations of daily child care responsibilities and Sara's list included more items of personal development for family members. All but one item of Phillip's ("doctors appointments") were included in Sara's.

Sara and Phillip together indicated in 64% of their responses that the characteristic listed on the scale was "sometimes" or "often" like their family. These response indications are found more often for Phillip (20) than for Sara (13).

2. Family Needs Scale: (Table 2)

This scale tries to delineate specific needs of the family. Phillip indicated 12 items and Sara indicated one item as "non-applicable". In addition, Phillip left 15 items and Sara left one item unanswered. This means that 13 of the 41 items (32%) were answered by both parents. Of these, 5 items (39%) elicited responses which were identical or within one value point; and 8 items (62%) showed responses two or more value points apart. In each of these instances, Sara indicates a greater feeling of need than Phillip:

# 1 having money to buy necessities and pay bills
# 2 budgeting money
# 4 saving money for the future
# 12 completing chores, repairs, home improvements
13 adapting my house for my child
19 transporting my child
21 finding someone to talk with about my child
35 having time to take my child to appointments

Sara and Phillip together indicated in 63% of their total responses that they "sometimes", "often", or "almost always" have the need articulated by the questionnaire statement. Sara indicated these needs more often (29 responses) than did Phillip (2 responses). In total, Sara indicated 15 items where she feels a need "almost always":

# 1 having money to buy necessities and pay bills
# 3 paying for special needs of my child

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4 saving money for the future

12 completing chores, repairs, home improvements

21 finding someone to talk to about my child

26 finding special dental and medical care for my child

29 caring for my child during work hours

30 having emergency child care

# 31 getting respite care for my child

# 32 finding care for my child in the future

# 34 getting equipment or therapy for my child

# 35 having time to take my child to appointments

# 36 exploring future educational options for my child

# 39 doing things with my family

# 41 travelling/vacationing with my child

Phillip indicated one item where he feels a need for help or assistance "almost always":

# 35 (having time to take my child to appointments).

3. Family Resource Scale: (Table 3)

This scale tries to determine whether or not a family has adequate resources of time, energy, and money. Its focus is on the family as a whole, as well as on individual members. Sara responded to all of the items. Phillip indicated one item as "non-applicable" and ignored one item. Of the 29 items that both answered, 17 responses were either exactly the same or within one value point. This indicates agreement or near agreement on 59% of the items. Together, Sara and Phillip indicated in 23 of their 60 total responses (38%) that resources articulated by the questionnaire statement are "seldom", "sometimes" or "not at all" adequate. Sara indicated these more often (20 responses) than did Phillip (3 responses). This represents 65% of Sara's total responses and 10% of Phillips total responses. Sara definitely feels resources are less adequate for this family than does Phillip. They agreed or were within one value point for three of these items (all of the ones that Phillip marked as "seldom" or "not at all" adequate):

# 18 time to be with close friends
# 30 money to save
# 31 time and money for travel/vacation.

In addition, Sara indicated the following items as "sometimes" adequate:

# 3 Money to buy necessities
4 Enough clothes for your family
7 Money to pay monthly bills
10 public assistance
11 dependable transportation (own car or provided by others)
# 14 time to be by yourself
# 20 babysitting for your child(ren)
# 23 dental care for your family
# 25 time to socialize

She listed the following items as "seldom" adequate:

# 15 time for family to be together

# 16 time to be with your child(ren).

# 17 time to be with your spouse or partner

# 18 (see above)

# 21 child care/day care for your child(ren)

# 26 time to keep in shape and look nice

Lastly, she listed the following items as "not at all" adequate:

# 22 money to buy special equipment/supplies for child(ren)

# 28 money to buy things for yourself

# 29 money for family entertainment

# 30 (see above)

# 31 (see above)

Lastly, there were 12 items where Sara and Phillip gave responses more than one value point apart:

# 3 money to buy necessities

# 4 enough clothes for your family

# 11 dependable transportation (own car or provided by others)

15 time for family to be together

# 16 time to be with your children

17 time to be with spouse or partner

20 babysitting for your children

# 21 child care/day care for your children

# 22 money to buy special equipment/supplies for your child

# 26 time to keep in shape and look nice.

28 Money to buy things for yourself

29 Money for family entertainment

In each of these instances, Sara gave responses indicating greater need than did Phillip.

4. Family Support Scale: (Table 4)

This scale tries to delineate sources of support for the family. Phillip indicated 2 items as "non-applicable" while Sara indicated none. Phillip left 6 items unanswered and Sara left three. Both parents responded to 12 items. Of these twelve items, 6 responses were identical and 6 were within one value point. This indicates 100% agreement or near agreement for Sara and Phillip on this scale. Of their 29 responses, however, 15 (52%) are at the low end of the response scale ("sometimes helpful" and "not at all helpful") and 10 are at the high end of the response scale ("very helpful" and "extremely helpful"). While Sara and Phillip indicate some good support in their lives, it must be noted that more than half of the "help" that Sara and Phillip receive is not very helpful.

Lastly, Sara responded to five items that Phillip ignored or indicated as "non-applicable":

# 11 parent groups
# 13 church members/minister
# 14 my family or child's physician
# 15 early childhood intervention program
# 18 professional agencies.

Items #11 and #13 were categorized as "sometimes helpful"; item #18 as "generally helpful"; and items #14 and #15 as "very helpful". It's hard to discern from these data which of these parents feels more supported. Certainly Sara gave more responses of low value (9) than did Phillip (6) indicating more "sometimes helpful" or "not at all helpful" experiences.

5. Personal Network Matrix; (Tables 5 and 6)

This scale tries to delineate people or groups with whom each parent had made contact in the previous month and the perceived level of their support. Sara and Phillip completed parts A and C of the scale.

For part A, Phillip answered 19 items and Sara answered 23 items. Of the 19 items that both answered, responses were exactly alike for 8 items and within one value point for 7 items. This indicates total agreement or near agreement for 15 of 19 items (79%). In other words, both parents have contact with approximately the same group of potential supporters. There were four items where responses were two or more value points apart:

# 10 church members

# 12 co-workers

# 15 private therapist for child.

# 21 other agencies

For Items #10 #12 and #21, Sara indicated more frequent contact than Phillip. For item #15, Phillip indicated more frequent contact than Sara. These differences probably reflect different interests and different family responsibilities for each parent.

For the two open-ended items (#22 and #23), Sara indicated two groups, Overeaters Anonymous (OA) and Al-Anon as sources of personal support for her. Phillip left these items blank.

Those items indicating frequent contact (Ten or more in the past month) are as follows:

1 spouse or partner
2 my children
3 my parents
5 my sister/brother
8 friends
10 church members
12 co-workers
13 baby sitter
14 day care or school
15 private therapist for child
21 other agencies
22 OA support group

Sara had considerably more contact with people outside of the home than did Phillip.

For part C, Phillip answered 15 and Sara answered 21 of the 23 items. For the fifteen items where both parents answered, they gave the same response for four items and responses within one value point for 11 items. This indicates agreement or near agreement for all items answered by both parents. For eight of their 36 total responses, (22%) they indicate that one or the other could depend on the selected sources of support "most of the time" or "all of the time". Sara indicated that they could count on "other relatives" (#7) "not at all" and Phillip gave the same rating to "minister, priest, or rabbi" (#11). Sara responded to six items that Phillip ignored:

# 16 child/family doctors
# 17 early childhood intervention program
# 18 hospital/special services
# 19 health department
# 20 social service department
# 21 other agencies.

Except for #16, which she categorized as helpful "most of the time", these items were categorized as "occasionally" or "sometimes" helpful. Neither Sara nor Phillip offered names of any agencies for items #22 and #23. Only one item (#1 "spouse or partner") was indicated by both partners to be dependably supportive "all" or "most of the time". In addition Sara indicated four items that she felt were supportive "most of the time":

# 2 my children
# 13 baby sitter
# 14 day care or school
# 16 child/family doctors

Phillip indicated two additional items where he felt supported "most of the time"

# 3 my parents
# 4 spouse or partners parents

In general Sara experiences more support from contacts outside the home than does Phillip.

6. Inventory of Social Support: (Table 7)

This scale and its matrix attempt to delineate people or groups in the lives of respondents who supply help or assistance, when asked. Phillip responded to answered 14 of 20 items (70%) while Sara answered all 20. Of the 14 items that both answered, responses were the same for 8 items and within one value point for 4 items. This indicates agreement or near agreement for 86% of the items answered by both parents. Only two items were two or more value points apart. For item #11 ("co-workers") Sara indicated more frequent contact than Phillip and for item #13 (private therapist for child) Phillip indicated more frequent contact than Sara. These differences probably reflect their different family responsibilities. Finally, Sara responded to six items to which Phillip gave no response:

# 15 early childhood intervention program
16 health department
17 social service agencies
18 other agencies
19 (open) "Overeaters Anonymous
# 20 (open) "Al-Anon".

Frequencies for all these items was given as "once or twice" except for #16 which was categorized "not at all" and #19 which was categorized "at least 10 times".

Sara made a total of 32 "checks" on her matrix and Phillip make a total of 40 "checks". Data from the matrix indicate that for Sara, the greatest sources of support are herself (8 checks) and her spouse (6 checks). Phillip's greatest sources of support are Sara (10 checks) and their children, his parents, and Sara's parents (each with four checks). Their perceptions of Shane's acceptance vary widely, however. Sara sees him accepted, regardless of how he behaves, only by the immediate family (3 checks... mother, father sister); whereas Phillip sees him accepted by almost every possible contact person or group (15 checks).

7. Support Functions Scale: (Table 8)

This instrument tries to find how much help and assistance respondents need in each of twenty different areas. Both Sara and Phillip answered all twenty items of this scale. Two of their responses were the same and 10 were within one value point, indicating agreement or near agreement for 60% of the twenty items. Responses to eight items (40%) were two or more value points apart. In each instance, Sara indicated greater need than did Phillip:

# 2 someone to provide money for food, clothes, and other things
3 someone to care for your child on a regular basis
4 someone to talk to about problems with raising your child

# 7 someone to fix things around the house

# 8 someone to talk to who has had similar experiences

# 9 someone to do things with your child (unpaid)

# 11 someone to hassle with agencies or businesses when you can't

# 12 someone to lend you money.

Together Sara and Phillip provided 40 responses to this scale. Nine of these (23%) indicated the need for help or assistance "often" or "quite often". All of these responses were made by Sara:

2 someone to provide money for food, clothes and other things

3 someone to care for your child on a regular basis

4 someone to talk about problems with raising your child

# 7 someone to fix things around the house

# 8 someone to talk to who has had similar experiences

# 9 someone to do things with your child (Here Sara wrote in not paid)

# 11 someone to hassle with agencies or business when you can't

# 12 someone to lend you money

13 someone who accepts your child regardless of how he acts

Of the 40 total responses made by this couple to this questionnaire, 9 (23%) indicate needs "often" or "quite often". All of these responses were made by Sara. On an individual basis almost half (45%) of Sara's responses indicate nneds "often" or "quite often".

8. The Matrices of Scales 2 and 6

Our family discussion, including the MAPS planning, took over three hours. Everyone took part. Because of the late hour, I elected to omit the discussion concerning concrete "projects" and possible support for the family to help accomplish the projects.

Summary

The questionnaire data confirm the information that Sara had already provided through interviews. In general this couple is providing good support to each other.

While Sara and Phillip show considerable agreement, there are some areas which indicate different perceptions and a level of greater need on Sara's part as compared to Phillip. At the same time, Sara seems to feel a greater amount of support from outside the family than does Phillip. This family is coping with many problems and Sara has actively sought and made use of existing support services. Data indicate that Sara assumes a large part of the daily family concerns; but Phillip carries a large part of the daily household and childcare responsibilities. While this couple provides good support to each other; they indicate a somewhat limited experience of support from outside the family. At least, they have had to work very hard to find the services and support that they are receiving.

THE MAPS PLANNING SESSIONS

MAPS planning (Forest and Lusthaus, 1990) consists of discussion by interested parties around seven questions. Family responses to these questions are summarized below.

Family # 1

The MAPS planning session with Martha and David went very well. They invited Mary Winston to join us. Mary has been very supportive of this family in the past and was instrumental in getting a "Circle of Friends" started for Bruce in his junior high school years. She was a good resource to enrich our planning. I can't help but state, however, that I feel this kind of planning is somewhat redundant for parents like Bruce's. They have experienced many planning sessions. While I detected a bit of skepticism of the value of this additional session on David's part, he was a good sport and contributed throughout the evening. We looked on the session as useful for this research; but also useful for this family as a means of getting their plans for Bruce up-dated and as an opportunity to "practice" for future planning sessions concerning Bruce's education and transition to the adult world.

It is suggested (Forest and Lusthaus, 1990) that each child's "Circle of Friends" be included in every MAPS planning session. We did not do this because of the nature of the research and its family focus. However, the omission of Bruce's "Circle of Friends in this instance should not be interpreted as the norm for planning for Bruce in the future. Rather, his "Circle of Friends, because they are so critical to Bruce's functioning, should be included, if possible, whenever planning is done for him.

The following is a summary of the responses to each of the questions:

WHAT IS BRUCE'S HISTORY?

David and Martha reiterated Bruce's history, adding a few more details and a few additional elaborations. In general, Bruce displayed behaviours early in life that indicated developmental delay and neurological damage with seizures. David's first marriage broke up early in Bruce's life and custody of him and his two older brothers was awarded to their natural mother. When Bruce was four years old, she placed him in a residential institution where Martha was one of his caregivers. In the years following Bruce's placement in the residential institution, David and Martha met and later married. When Bruce was nine years old, David started legal proceedings to gain custody of Bruce. After two years of struggle, David was awarded custody in an out-of-court settlement. By that time David and Martha had been married and Bruce came to live with them on a twenty-four hours a day basis. It was at that time that Bruce received his experience of public school. He spent a year in a segregated special class at the elementary school level and then was placed in a junior high school special class. By the last year of his junior high school experience, he had a "Circle of

Friends" and spent about 50% of his time in regular classrooms. David and Martha had hoped that this type of programming would continue at the senior high school level; but such has not been the case. This disappointment in the kind of educational programming for Bruce along with Bruce's serious illness last year, were a source of recent extra stress for this family.

WHAT IS YOUR DREAM FOR BRUCE?

While Martha was the most talkative when we discussed this question, both David and Mary expressed their dreams for Bruce. All hoped for good health for Bruce and a continuation of the good control of his seizures that has been achieved since his hospitalization four months ago. They also dream of good friends in Bruce's life, and that he not be rejected. They hope the focus of people around him would shift away from all the things that are wrong with him and toward all the things about Bruce that are positive and that show his ability to learn and to grow. They want something meaningful for him to do outside the home, some kind of work, eventually; and they want other people in his life, besides his parents, who will take time to get to know him and to appreciate what he can do and what he can give to them. They believe that he functions best in a family setting in the presence of people who can "read" what he communicates, and therefore hope to have him live with them always. They recognize that such a dream will require help and support from other people and more adjustments to their own lives, as they age. In the meantime, they hope for supported schooling for Bruce with people who care for him and who will allow him to learn according to his own interests in the mainstream of the school environment. They hope, as well, for some kind of tertiary education for Bruce where he can learn vocational skills and be helped to make the transition to the adult world.

WHAT IS YOUR NIGHTMARE?

In general, their nightmare is the opposite of their dream. They worry about what would happen to Bruce if something should happen to them. They noted that, in a sense, the past year was a nightmare because of Bruce's illness and the school's inability to accommodate a student with Bruce's needs.

WHO IS BRUCE?

For these parents and for Mary, all of whom know Bruce very well, Bruce is a loving, energetic, happy young man. He loves to be exposed to new things and to learn about his world. He knows how to get what he wants. He has genuine and distinct likes and dislikes. He shows his likes by enthusiasm and his dislikes by withdrawing or showing disinterest. Bruce has a good sense of humour and sometimes likes to tease. As well, he likes to please people and is especially responsive to people that he thinks have positive feelings towards him. He loves music and playing with "boy toys". He likes people and wants to be with people. He loves his home and loves to be with his parents. He has genuine feelings and many "normal" traits, all of which have to be "read" by those around him, because of his inability to use verbal expression for communication. In the right setting and with the right people, he learns quickly and is willing to take risks, as exemplified by his learning of computer skills this past summer.

Of all these traits, the ones that David appreciates the most are his loving nature, his ability to communicate his likes and dislikes and the fact that he has genuine feelings and can express them. Martha appreciates that he is so much a "people person"; that he has so many "normal" qualities, if one learns to "read" Bruce's behavioural communications; and that he internalizes his experiences. The latter trait has both advantages and disadvantages. It is an advantage because this is how all people learn; but it is a disadvantage because Bruce can get his feelings hurt, which is complicated by his inability to verbally express what he is experiencing.

WHAT ARE BRUCE'S STRENGTHS, GIFTS AND TALENTS?

We didn't spend a great deal of time on this question because we felt we had covered it when we discussed,"Who is Bruce?". Martha feels that Bruce's greatest gift is his way with people. People like him; he can be lots of fun. David feels one of his major strengths is that he wants to learn and is excited when he has an opportunity to do new things and learn from new experiences.

WHAT ARE BRUCE'S NEEDS?

Bruce needs to be with people who understand him, people in addition to his parents. He needs to be in a school situation where he can feel good about himself and learn within a social environment. He learns a great deal from other people; he models what they do. He needs a more balanced life, one that is more typical for a person of his age. He needs more appropriate social/recreational activities: things that he can do by himself, at home; things that he can do with others, apart from his parents; things that he can share with others.

WHAT WOULD BE AN IDEAL DAY FOR BRUCE?

We divided our discussion into "weekday" and "weekend", in order to address an ideal school day and an ideal day at home. David and Martha would like to see more independence in getting ready for school and in getting to school. (Bruce would dearly love to go to school on a school bus!) They would like to cut down the amount of time (currently about 90 minutes) that it takes to get Bruce ready for the day. At school they would like to see much less special education and much more programming within the mainstream environment of the school and more teaching within the social environment of the school. They'd like to see Bruce come home by school bus except for the times when he might stay for some extra-curricular activities. They'd like to see him in the classroom every day with his "Circle of Friends". Lastly, they'd like to see him have something to do in the evening; perhaps something on a regular basis, once a week, and one other night a week for some kind of spontaneous adventure.

For the weekend they'd like to have a little bit of leisure and a slower pace. Bruce will sleep late, to 9:00 or 10:00, and can usually find something to do until lunch time. He enjoys the Saturday shopping and can take part in it very well. On Sunday, it would be nice if he could spend a few hours off on his own, with a friend.

Family # 2

This session went very well. The whole family was present: Anne and Sam and their three children; Wayne (13), Terrance (10) and Marianne (9). The boys , especially Terrance, were active participants and had many good things to offer. The session lasted for about 90 minutes. It was the first time that this family had done a MAPS planning session. The following is a summary of this family's responses to each of the questions:

WHAT IS MARIANNE HISTORY?

Marianne was born nine years ago. When she was only a few days old, she was identified as having Down syndrome. In addition, she was born with two dislocated hips and a heart defect. The hips were repaired through bracing and physical therapy and the heart defect was repaired by open heart surgery when Marianne was five years old. From birth until her heart surgery, Marianne experienced many illnesses, mostly having to do with respiratory infections and croup. She was often found in respiratory distress. Since her heart surgery, she has enjoyed much better health. She has mild vision and hearing problems for which she wears corrective lenses and a hearing aid in one ear. She is very delayed in expressive communication because she speaks only a very little. Her language comprehension, however, is excellent. Marianne and Anne have been instructed in signing to assist her in communication. In addition, other forms of alternative communication are being explored, though speech continues to be a long term goal for Marianne.

Marianne attended day care for "early intervention" and as respite for Anne for three mornings a week, when she was three and four years of age. She experienced Kindergarten in the same day care centre when she attended for five mornings a week, at the age of five. She attended grade one for two years in her neighborhood school. She now attends grade two in the same school. She reads and takes part in all primary school activities. In addition, she likes to swim and skate, to shoot baskets with her older brothers, and to play with friends in the neighborhood and at school.

WHAT IS YOUR DREAM FOR MARIANNE?

Ideally, this family would like to see Marianne eventually living as independently as possible. They are not "sold" on group homes and would rather see her in her own apartment, with someone checking on her, periodically. They intend for her to go as far as possible in the mainstream of the school system. They see school as the basis for training and view her eventual attendance at the local workshop as preparatory for community-based employment. They hope that someday Marianne will talk or will have an efficient means of alternate communication. They see her communication disability as the most serious problem for her now, and possibly into the future.

WHAT IS YOUR NIGHTMARE?

Like most parents of disabled children who likely will not ever be able to live completely independently, Anne and Sam's nightmare is haunted by the question, "Who will look after her after we are gone?" They dread the thought of her having to live in an institution. A lot of time energy and money has gone into getting her to where she is and she functions well where she is. Their biggest nightmare is the institution. As well, they see the ability to communicate with anyone (not being dependent on the other person's knowing how to sign) as a key factor in her eventual independence.

WHO IS MARIANNE?

For these parents and for Marianne's brothers, Marianne is an active and loving person who sometimes can be wilful and stubborn; but who also has many other characteristics. She can be very funny. She loves to be with people; but she also likes and can make good use of solitude. Sometimes she can be bossy and can be a "handful" to manage; and she can be "scary", by wandering off. At the same time she can be generous, helpful and playful. She loves music and, like most little sisters, she loves to follow her big brothers around in their activities. Lastly, she's a good imitator and is eager to learn. Of these characteristics, Anne indicated "stubborn", "lovable" and "a good worker" as Marianne's most important defining characteristics, while Sam indicated "lovable", "active" and "lover of music".

WHAT ARE MARIANNE'S STRENGTHS, GIFTS, AND TALENTS?

While stubbornness might be viewed as a negative characteristic, it also has its positive side. In the right situation, it can be viewed as determination. In Marianne this is a very big strength, for she does not give up easily, not even on those things that she finds difficult. As well, Marianne has a charm that makes her appealing to others. People like her. She's friendly and can be cooperative. When she's in a stubborn mood, she won't do anything; but when she's in a good mood, she'll do anything. Anne pointed out that some of her moods may be a reflection of the frustration she feels because she has such difficulty in communicating her feelings.

WHAT ARE MARIANNE'S NEEDS?

Marianne's most pressing need is to be able to communicate her feelings better. She needs other people to know that she is no different than any of us, in her needs to be involved in the life around her. She needs to learn how to recognize possible dangers, however. She needs to have included into her current opportunities, some social-recreational activities that she can do independently with children her own age. Though her current friendship network is good, as she grows older she will need the opportunity to increase this network of friends and to increase her social and recreational independence. Eventually she will have to learn all the skills necessary for living as independently as possible.

WHAT WOULD BE AN IDEAL DAY FOR MARIANNE?

We divided our discussion into two parts, "weekday" and "weekend", in order to address the ideal school day and the ideal day at home. Ideally, Marianne's family would like to see her be ready on time to go to school; to not "dawdle"; and to not be "stubborn". When she's ready, they'd like her to get to and from school independently. They'd like her to have a good day at school and to be able to tell them about it when she gets home. It would be nice if she had some independent social-recreational activity several days a week. Lastly, they'd like her to be a little easier to get to bed when bedtime comes.

The weekends are already relatively "ideal". The family is pretty active and Marianne takes part in all activities. This is the time when Sam takes on more supervision of all the children's activities. It would be nice if, in addition, Marianne could have her own community outings with some of her friends, that she could do independently, as her brothers often do. Ideally, this would be something that her parents would not have to initiate.

Family # 3

The MAPS planning session for Shane went very well. In addition to Sara and Phillip, the session was attended by Shane's special (day care) teacher, Elaine Rhodes. Elaine has been very supportive of Sara in many instances and has been very successful in teaching Shane. As well, she has a non-verbal child of her own. Her daily living experiences with her own son, who is a 10 years old, has provided some invaluable information for Sara. In addition, Elaine has been a good support for Sara when she must interact with professionals in planning meetings to meet Shane's educational and developmental needs.

This is the first time a planning session like this has been held for Shane. It gave an opportunity for discussion to the three adults who are probably most involved with Shane, on a daily basis, and most involved in thinking and planning for Shane's future. I think, as well, it gave them an experience which provided "practice" and "preparation" for meetings with school personnel and other professionals, as Shane makes the transition to school. Everyone took part in the discussion of all questions, except for Phillip who missed a large part of the discussion of the last question. He initially left the group to have a cigarette and then to look after children's needs. He did not return to the discussion. I don't think anything happened to precipitate his departure from the discussions. I think he simply had had enough. (The discussion of all questions was lively and fruitful, but required almost two hours to complete.)

The following are summaries of the responses to each of the questions:

WHAT IS SHANE'S HISTORY?

Shane and his twin sister were born in July of 1986. At the time of their birth, Margaret appeared to be in good health but Shane was believed to have a mild heart defect. Very early in

Shane's life, however, he began to make little jerking motions. When Sara called their family physician's attention to these, she got very little satisfaction. It was not until she used the word "seizure" that the behaviours were examined seriously. When Shane was five months old he was sent to the JB Children's Hospital in Regional Centre, where it was decided that something was definitely wrong. Infantile spasms were ruled out and Shane was put on medication to control the seizures. When Shane was nine months old it was determined that his seizures were caused by neurofibromatosis. As with most children with seizures, it took a lot of parental observation, patience, determination, and many interactions with physicians to find the right combination of medicines to give Shane seizure control and still allow him to be alert and functioning during his waking hours. In Shane's situation, both parents were involved in this monitoring and adjusting. Shane's seizures have been well controlled for about the last nine months. Since then, he has grown and developed at a rate which pleases his parents and his special teacher; but he is developmentally delayed. Most particularly, he is delayed in his ability to communicate. Margaret is developing normally.

WHAT IS YOUR DREAM FOR SHANE?

For Shane to live as independently as possible (at all stages of his life) was a high priority in the dreams of all discussion participants. Also high on their lists of dreams is their hope that Shane will learn to communicate. While signed English is being used with Shane at the moment, everyone hopes that he will eventually speak. In addition, discussion participants dream that Shane will be happy and healthy; that he will someday have a job; a network of friends; and will be as normal and self-sufficient as possible.

WHAT IS YOUR NIGHTMARE?

The worst nightmare for Shane's parents would be that the neurofibromatosis would get worse. They recognize all the implications that would flow from a worsening of his condition. They dread loneliness for him and also dread institutional life and its loss of human rights. Having to be in an institution and not having friends is the nightmare of Shane's parents and current teacher.

WHO IS SHANE?

Shane's parents, and Elaine, all of whom know Shane very well, initiated at least twenty descriptors of Shane. These include handsome, loving, mischievous, determined, impatient, sometimes lonely, fun-loving, curious, busy, inventive, good sense of humor, nice smile, laughs a lot, charming, manipulative, "laid back" attitude, not shy, and intelligent. They also pointed out that if others have a low expectation of him, he is willing to comply with that expectation. Of these descriptors, Sara indicated that she felt "curious", "not shy", and "intelligent" would best describe Shane in terms of his achieving as much independence and self-sufficiency, as possible. Phillip indicated "determined", "fun-loving", and "intelligent".

WHAT ARE SHANE"S STRENGTHS, GIFTS, TALENTS?

Discussion participants indicated many strengths in Shane. Probably foremost in their minds was Shane's determination and the fact that he is not shy. He displays his intelligence by trying to figure out alternate solutions to problems that he encounters in his play and in his "work" at day care. He has good eye-hand coordination, finger dexterity, and a good memory. Phillip stated that he wonders if Shane can see in the dark because Shane will often go climbing in the basement without turning on the lights. Both parents remarked about his good balance and his prowess in climbing. Shane is "easy going" and possesses a sunny disposition. Lastly, he displays good imitative abilities. All are optimistic that these qualities will help Shane to learn and develop, now and in the future, so that he will eventually achieve a large measure of independence.

WHAT ARE SHANE'S NEEDS?

Shane's most pressing current need is a well coordinated case conference including representatives from occupational therapy and speech therapy, Shane's family support worker, the day care supervisor, Elaine (who will be going with Shane to grade 1), Sara, Phillip, and a representative from the school division. At this case conference the group should delineate realistic long-term goals for Shane (to the extent that this is possible) and short-term goals. They should establish priorities and then agree to work toward these goals and priorities. There is a need to establish/maintain good communication between all the represented disciplines and individuals. Within this framework of a good parent-professional working group, our discussion indicated that Shane's greatest need was for help with communication and the establishment of reliable communication skills. Other important needs include the need for establishing and enlarging a network of friends; the need for a special someone to fuss over Shane and invite him to his/her home in the same way that Margaret has a special aunt who does these things for her; and the need to improve Shane's social skills. It should be noted that we believe all of these needs could be met with thought and careful planning. Sara and Phillip expressed ideas of how they could initiate some activities that might begin to establish some friends for Shane in the neighborhood. Elaine gave suggestions of children at day care who are interested in Shane and who include him into their activities.

WHAT WOULD BE AN IDEAL DAY FOR SHANE?

As was the practice with the first two families of this study, we discussed this question first in terms of a weekday (particularly a school day next year in grade 1) and then in terms of the days of the weekend.

For a school day, Sara would like to see Shane able to get ready for school, as independently as possible. She and Elaine would like to see him ride the school bus independently and Sara would prefer the initiation of a "buddy system" to help Shane, as opposed to simply strapping him into a seat. They would like to see him included in the regular grade 1 program; play outside with the kids; and eat lunch with his friends. They hope that he will pay attention to what is going on in the classroom and to what is expected of him. Elaine, supported by Sara, hopes that the one-on-one instruction that she gives will become increasingly only support and direction. This would help Shane to grow in independence. At the same time, Elaine could function more as a support to the whole class rather than someone assigned only to Shane. They hope that Shane will return home independently, by school bus; that he would occasionally have an after school activity (Beavers or Cub Scouts?) to attend but would have time, most days, to play with his friends; that he would eat supper, do his homework, perhaps enjoy a bit of television and then go to bed. Perhaps on Friday night, he would occasionally visit overnight with someone, as Margaret does now.

Over the week-end, Sara would like to see him "sleep-in", a bit, on Saturdays, enjoy some television cartoons, and help with household chores (straighten bedroom, pick up toys).

Perhaps he could learn to prepare some simple meals for himself...choose what he wants and make it. Saturday afternoon is a time for them to do something as a family, and Sara would like Shane to enjoy these activities. Because Saturday night is time set aside for Sara and Phillip to be together, it would be ideal if Shane could enjoy being with a sitter. Sundays are usually spent at Sunday School and making visits to extended family members. Achievement of these ideal days are not far away. Shane is already doing most of these things. Areas where

Shane needs to learn some skills in order to totally achieve this ideal are: skills of independence; skills of helping around the house; and motivation or development of interest for enjoying television. All felt these skills could be learned and that effort in that direction could begin immediately.

DISCUSSION

Undertaking this research has been both demanding and rewarding. It has required all the labour and attention to detail that research requires, in general, as well as the special demands of qualitative studies. Studying phenomena in depth has its special rewards, however. In this case, the study has opened special areas of information and social perceptions that had not been previously so readily available to me. It has been a good experience.

Overwhelmingly, my response to the experience is considerable awe and respect for how courageously and competently these parents have risen to the occasion of child disability within their family circles. They are an impressive group. The most all-pervasive feeling that I have from the data of the study is a deep respect for the parents' abilities to manage the many and varied demands on their time and energy which result from their children's disabilities. At the same time I am deeply disturbed at the number of times that these parents have been let down by professionals. Yes, they describe many good experiences with professionals, and we need to examine these carefully; but there are too many occasions in the data when professionals have made the lives of these parents needlessly more difficult. I find descriptions of professional neglect, disinterest, or rejection very distressing.

We should be the strongest allies of parents, working with them to provide for the best possible opportunities for growth and development in their children, and supporting them in their struggles to meet the needs and improve the quality of life of each of their children. The discussion below examines the study data in the light of this understanding, and highlights the major elements in the very complex family, professional, and societal interactions revealed by the study.

Histories

While each of these families has its own individual characteristics, in many ways they represent the mainstream of Canadian-born and North American life. These are well-functioning, two-parent families. They are not rich; but they live comfortably in pleasant and modern surroundings. They are Canadian-born and they are not members of a racial or ethnic minority. All of the parents are articulate and well educated. The only factor that makes these families different from the mainstream (as it is currently perceived) is the presence in each family of a child who is disabled, and thus developmentally different from most children of their same chronological ages. The children are Bruce, age 18; Marianne, age 9; and Shane, age 5. Bruce has older siblings, but because of marriage breakdown and different custodial arrangements, Bruce has not lived with his siblings since he was a young child. This is the second marriage for both Martha and David. David is Bruce's natural father. David and Martha have been together for about a decade. The other couples in this study, Anne and Sam, Marianne's parents, and Sara and Phillip, Shane's parents, are each in first marriages. Marianne has two older brothers, living at home, and Shane has a twin sister, living at home.

Money is seldom a problem for Bruce's family. His parents are the oldest of this group of parents and both are working. Bruce is the only child living at home. This is not to say that they don't have to watch where their money goes. Rather, it is to say that they are not struggling to make ends meet. Marianne's family has to be more careful about money. There was only one full-time paid worker in their family at the time of this study and there are three children living at home. But Anne and Sam are good managers. Husbanding economic resources is something that they must do; but they are not struggling financially. Shane's parents, Sara and Phillip have more financial worries than the other parents. They are the youngest parents and are in that age group (25-35) which has had a very difficult time finding employment in North America in the past decade. Both parents were working at the time of this study. All three families are paying for childcare for their disabled children, though for varying amounts of time. Because Anne was not working at the time of this study, paid child care for Marianne was quite minimal. Both Bruce and Shane, however, were receiving paid child care on a regular basis because of parental work schedules. All three fathers in these families share in child care and other domestic responsibilities. While they probably do not shoulder 50% of these responsibilities (Phillip might), they do make a major contribution to this part of family life.

All three of the children with disabilities have had periods of very great illness. These have been a major drain on family resources of time, energy and money. In all three cases, the mothers of these families, more than the fathers, spent time and energy on the health care demands of the children. This is not because the fathers are neglectful or disinterested, but because the fathers are tied more than the mothers (Sara might be an exception here) to jobs that maintain each family's economic base. I detected no resentment, on the part of the mothers, which might reflect paternal neglect or disinterest concerning their children's illnesses. All the mothers indicated that they felt supported. One mother, Sara, felt that she had unwittingly "taken over" with regard to her child's health care needs and wished that those involved with Shane's medical problems had helped her to include Phillip in the early processes. She also indicated that appointments have to be taken at the convenience of the professional. There is little or no opportunity to make appointments when both parents might be available. For two of these families, health care problems continue. Happily, Marianne's health has improved markedly since her heart surgery at age five.

At the time of this study, two of the children presented disabilities that would probably be regarded as "severe" or "profound". Bruce, at 18 years of age, was still working on toilet training and was not yet communicating with words. Shane presented many autistic behaviours and problems of communication. Like Bruce, he was not yet toilet trained. Because of his young age, however, it would be a disservice to label him with any level of disability. We have to "wait and see". More importantly, both Bruce and Shane are showing that they are learning, especially when in the presence of people who make appropriate adaptations for them and work at "reading" their behaviours as indicators of communication. Marianne is the child in this study with the least handicap. While she has Down syndrome, her major disability is in the area of communication. She is in a regular classroom in her neighbourhood school. She reads, writes, and does most of the things that children her age can do, except for speech. In order to communicate to people outside her immediate family, she must sign. This, naturally, limits the number of Marianne's communication partners. With time, and with an alternative communication device, Marianne will likely be regarded as only minimally handicapped.

All three families spend much time and energy getting appropriate and mainstream schooling for their children. This is especially true for Bruce's parents, but both Marianne's parents and Shane's parents do as well. Martha and David will not go to meetings concerning Bruce at the school unless both can attend.

David is very supportive of Martha and they present a united front in their interactions with the school. Marianne's and Shane's mothers handle most of the interactions with the schools. Both Sam and Phillip support their wives in their struggles to get appropriate schooling for their children, and attend meetings at the school when it is obvious that their presence is needed. In general, getting appropriate schooling in the mainstream has been the biggest problem for Bruce's parents and the least problem (so far) for Shane's parents. Marianne's parents' struggle has been somewhere "in between" up to now, but Anne feels the situation is quite fragile and requires constant monitoring.

All three families spend much time and energy finding social and recreational activities for their children. The children have friends, but varying levels of parental labour has gone into building these friendships. All of the parents believe friendship and social learning are very important components of their children's development. For Bruce, friendships have come about because of his Circle of Friends, which was inaugurated by a friend and co-worker of Martha's. Siblings have been a very real source of support and opportunities for friendship and social learning in the lives of Marianne and Shane.

These families look positively toward the future; but they have concerns about what lies ahead for their children. They hope for the greatest level of independence possible for all their children. They are realistic in their hopes, however, and try to be realistic in their expectations of schools and other service agencies. To a certain extent, all three of these families feel that "time is running out". Naturally, the parents with the oldest child feel this most intensely. They feel that their child has rights that are not being addressed. The parents of Marianne and Shane feel the time factor less intensely; but they feel more acutely that they have a long road ahead of them to get the developmental opportunities for their children that parents of typical children can take much more for granted.

Interview Data

1. The Children

a) descriptions

Bruce, Marianne, and Shane display inquisitive and active personalities. Each likes to laugh and play and each has individual patterns of play and learning. These children are able to learn; but those who interact with them need to make accommodations which take into account each child's individual learning needs and personality traits. Communication is a big problem for all of the children. Each family has searched for and continues to search for ways of making communication more available to their children. The challenge which these parents face, especially the mothers, is to find ways for their children to be included in the mainstream of life: meaningful schooling, opportunities for playmates and companions, socializing experiences, parties, sports -- whatever is "normal" for children of these ages. They recognize that their children, in varying degrees and in a variety of developmental areas, present specific challenges to whomever is involved with the children, but they know that the challenges are not insurmountable. The mothers are frustrated, I believe, by the amount of parental time and energy that is required to see that their developmental opportunities, which other children can take for granted, are available to Bruce, Marianne and Shane. They are frustrated, as well, by the very large expenditure of time and energy required to get services to meet their children's special needs.

b) friends and social learning

Bruce, Marianne and Shane have had varying success in establishing friendships. Like all parents, Martha, Anne and Sara believe friendships for their children are important. Each family works at finding opportunities for friendship for their children. Siblings have been an important link for Marianne and Shane in this regard. The "Circle of Friends" (Perske, 1988) has been a good support and learning opportunity for Bruce. In some ways, Bruce's Circle of Friends plays a role in his life which is similar to that which is played by the siblings of Marianne and Shane. But all three parents state that they have to remain continually involved in friendship building. There seem to be few people in the lives of Bruce, Marianne, and Shane who will spontaneously "include" these children on any kind of a regular basis. Mostly, activities have to be initiated by the parents, or there has to be some level of parental involvement. The

Circle of Friends has been wonderful for Bruce, but his parents are greatly disappointed in the fact that the educational personnel at Bruce's school assume no responsibility for helping Bruce and his Circle to meet during school hours, nor do they attach any particular importance to Bruce's having friends. Marianne and Shane are, as yet, having a bit easier time in friendship development, especially Marianne; but there is considerable parental involvement here, too. All three families hope for someone who would involve their children in a special way, through spontaneous inclusion.

2. Parental Stress/Anxiety

a) children's development

Like parents everywhere, the parents of Bruce, Marianne and Shane have many stressors in their lives. For the parents of these disabled children, however, the "normal" stressors last longer and take on a greater intensity. Toilet training is still an issue for Bruce and Shane. Communication continues to be difficult for all three children. All three can present behaviour difficulties, often resulting from frustrations associated with their communication problems. Marianne can be stubborn. Shane can demand things (e.g putting toys "together") which are impossible to do. Bruce will "tune out". All of these stresses can wear parents down.

b) illness/disability

Specific illnesses in their children, which have been more serious than the usual childhood illnesses, and, especially for Bruce and Shane, will continue indefinitely, bring serious stresses into the lives of these parents. The sleepless nights and daily concerns which all parents face with infants and young children have continued for considerably longer than is usual. Hospitalizations have been lengthy. Because of the nature of each child's illnesses, others have refrained from getting involved in any kind of direct way. As a result, these families and especially the mothers feel somewhat alone and isolated. Fortunately, Marianne's extreme illnesses are likely a thing of the past, and Bruce and Shane were quite healthy at the time of this study. While Sara is seeing indications of "hands on" help from extended family members, Martha saw only David as a likely help for her, should Bruce become seriously ill again. There is good reason to assume that both Bruce and Shane will continue to have serious health concerns. There is also good reason to assume that those health concerns will be addressed on a daily basis primarily by the people living in their households, with little "hands on" assistance by people from outside the immediate family.

c) illness/disability/financial

Even with universal health care, from time to time these parents feel financial stress because of the special needs of Bruce, Marianne or Shane. Travel expenses when a child is hospitalized in Regional Centre, room and board for the accompanying parent and other family members, telephone calls back and forth, babysitting for other children, diapers, special equipment, and medicine, all add up to additional expenses. Each family has found some help for these expenses (often after considerable work), and specific provincial services pay for some special needs; but expenses are not covered completely. As well, there is the additional "expense" for Martha and David, of caring for an adult with disabilities. While they do not expect to be paid for the care that they give to Bruce, Martha states there is "something wrong" when foster parents of disabled adults have fewer financial liabilities than natural or adoptive parents for doing the same thing. There is no recognition, let alone any kind of compensation, to natural or adoptive parents for saving tax money and for being on duty 24 hours a day to care for another adult citizen. Anne points out the financial differences, as well, between natural parents caring for a child with a disability in their home and foster parents caring for a foster child with similar disabilities.

d) illness/disability/parental work

Martha, Anne and Sara have ambivalent feelings about working outside of the home which are intensified by their children's disabilities. All three mothers expressed a personal need to work outside the home in order to have an opportunity to function in the adult world and as an opportunity to express themselves and their talents and skills. Only Sara implied a financial need to work outside of the home. Martha and Anne indicated that while the money is appreciated; if necessary, their families could live on the salaries of the fathers of their families. All the mothers spoke of their personal need to get away from the demands of the household, preferably at regular intervals. They spoke of work as being a place where other demands occupied their attentions, and that this diversion was a welcome change. At the same time, they spoke of the difficulties of finding employers who would accept their family needs for more than the usual number of appointments and meetings. They also talked about how employment for them, like most mothers, was highly dependent on adequate child care, and indicated that because of the nature of their children's special needs, this commodity was especially hard to get. While Martha and Sara (the two employed mothers at the time of this study) were very pleased with their current child care arrangements, each expressed concern over the desperate situation which would present itself, should they somehow lose their child care. Sara, with the youngest children, expressed her concerns about working full time. She worried that maybe she was trying to do too much. These mothers are paying a high price for opportunities to function in the adult world and for the ordinary rewards and valuing of adulthood, as do all women who move away from the traditional models of adulthood. The special needs of their children, however, present special problems and special anxieties, which have not been resolved, as yet. Societal attitudes and public policy on childcare issues and human disabilities continue to take a serious toll in these women.

e) isolation

These mothers express feelings of abandonment and isolation. While all three receive good support from their husbands, and all three have intimate friends outside of their immediate family circles, only Sara has found consistent support for herself and her problems outside her home. For the most part, Martha and Anne carry on their lives with little support and encouragement from people, apart from the people with whom each lives; Sara has found at least some of the extra support that she needs, and uses that support in ways that help all the members of her family. Part of the mothers' isolation comes, I feel, from basic ignorance on the part of others with whom these mothers must interact. People do not understand disabilities and their implications, and being human, they avoid what they do not understand. It is easier to leave the care of children and adults with special needs and their inclusion into the mainstream of life up to the "experts". Parents are quickly viewed (by the general public) as at least "quasi-experts", since they obviously know what to do. What the general population does not understand is that many of those who are perceived as "experts" do not support parents in the way that parents should be supported, especially if the parents want something (e.g. mainstreaming, speech and language training for non-verbal children) which is contrary to the "experts" notion of their professional competence, responsibility, or personal well-being. This kind of "abandonment" increases the parent's isolation. They are left to fend for themselves.

We can see how competent these mothers are. Despite the demands and the struggles, they are doing well, their families are doing well, but someone is paying a price here. One cannot help but speculate on what the results could be, in terms of quality of life for all family members, if there were a bit more "hands-on" support and accurate public understanding of the implications of child disability on family life. One cannot help but ask the question, as well, "If these well-educated, articulate, competent women, supported in many ways by their husbands and other children, are finding parenting and meeting the developmental needs of their children THIS emotionally demanding and time-consuming, what's happening in the lives of mothers of disabled children who are less advantaged? and what's happening to their children?"

f) additional stress

Sara is parenting children in a family with some special needs in addition to those which arise from the disabilities of one of the children. She has found satisfaction for these special needs in already existing services related to alcohol abuse (Al Anon) and/or eating disorders (Overeaters Anonymous). Sara has learned how to find these services and thus to find support for herself and her family outside of the family. Moreover, she generalizes the principles she has learned from these already existing support groups to the problem-solving she must face concerning Shane's special needs.

It would be difficult, I believe, not to be impressed with the way Sara is coping with the complexities of her life. She has used the problems that life has handed her as an opportunity for growth. While she has endured considerable insensitivity on the part of people who are paid to provide appropriate services to her and to her child, currently she has been able to find (largely as a result of her own initiatives) professional support that is truly providing her with a service. Her assertiveness has evolved out of the renewed self-confidence she has found in her twelve-step programs. She is energetic, focused, full of plans for the future, and is making decisions. As a result her family life is nourishing for everyone and is gently prodding all members to appropriate responsibility.

g) demands on parents

All three families find themselves facing many demands over and above the ordinary demands of raising a family. Moreover, these demands are often more intense and of greater duration than is usually the case in child-rearing. While the fathers in each of these families provide good emotional and practical support, many of the child care and family management demands and demands arising out of the special needs of Bruce, Marianne, and Shane fall primarily on the shoulders of Martha, Anne and Sara. This is a common problem. Even when all family members sincerely try to share all responsibilities associated with running a household, organizing the work and meeting with school or health professionals usually falls on the shoulders of mothers.

Meetings with service providers is a big demand on parents. The ideal is that meetings with service providers would take place only when both parents can be present. Martha and David can meet this ideal for school meetings, but it is easy to see that the ideal is impractical for most families, especially for meetings with other agencies. Parents are too busy and have too many employment demands. Professionals need to find ways of interacting directly with both parents, and of providing information to both parents and to other family members. Without a commitment to communicating with both parents, we risk turning one parent into the "family spokesperson" while leaving out the other parent. We also risk "ganging up" on the lone parent at our meetings. Since lone parents at meetings are usually mothers, we also risk being influenced by entrenched social attitudes which put mothers in a less favourable light than fathers or which allow mothers to command less of our attention than fathers are allowed to command. We need a societal change of attitude which recognizes and values the household organizer as much as it recognizes and values the principal provider of household economic resources.

3. Interacting with Professional

a) services, in general

Martha, Anne and Sara all relate what can only be termed "horror stories" of their treatment at the hands of some professionals. These mothers were made to feel inadequate, subversive, uncooperative, disheartened, overwhelmed, and to experience ongoing feelings of guilt as a result of some professionals' interactions with them and their children. Each mother has experienced, as well, very positive, supportive and productive interactions with some professionals. The difference in these two sets of professionals seems to be related to the particular attitude that each possesses concerning the child with a disability or, perhaps, concerning disabilities, in general. Professionals from whom these parents experienced negative interactions seemed to feel that the child with disabilities was not going to benefit from the service the professional had to offer or was not that professional's responsibility. The professionals with whom these parents experienced positive interactions seemed to be energized by the challenge of the children's disabilities and were willing to assume appropriate professional responsibility for services to be provided to the child.

What excuse can be found for professional abuse of parents such as has been described by these mothers? I can think of none. When we behave toward parents in these ways we have lost sight of our reason for employment. We have lost sight of the fact that our clients are the purpose of our employment, not our own personal egos or aggrandizement of our expertise.

On the other hand, the positive experiences which these mothers describe give us a clear picture of appropriate acceptance of professional responsibility and of appropriate client support and empowerment. "Empowerment" has taken on a distorted meaning in some circles; it is used, here, not in the sense of simply "letting the parents do it" (alone) but in the sense of capitalizing on the nurturing skills that parents already possess. Competent professionals do a lot of listening and learning, while offering additional suggestions and additional opportunities for parents to acquire more skills. "Empowerment" also means including parents in decision-making and teaching us (professional and paraprofessional service providers) about their child.

b) education, in particular

The services these families are receiving from educational institutions vary greatly. All three families want their children to be educated as much as possible in the "mainstream" of available educational services, and to have educational experiences which will meet their developmental and educational needs. As well, they feel that the mainstream educational system has a responsibility to make the appropriate adaptations to include their children. Bruce, the oldest and probably the most severely disabled child of the three, is currently having the most difficulty in obtaining appropriate educational services.

This was not always the case. During his junior high school years, Bruce's parents were very satisfied with what his school was offering Bruce. Marianne has had much more consistently appropriate and mainstreamed educational experiences than has Bruce. As well, she had a very successful and satisfying early intervention, kindergarten and grade one experience. Marianne, of course, is younger than Bruce and has probably profited from all the children like Bruce who have preceded her in the system, and from the pressure from their parents, who have helped to "shape" the educational opportunities which professionals are now willing to provide. As well, now that many of her health problems have been alleviated, Marianne is probably the least disabled child in this study. Her mother has worked very hard to obtain appropriate educational services for Marianne. She continues to monitor these services. Shane is just beginning school. He has had a very successful and satisfying early intervention experience at day care and mechanisms are in place to help him make a successful transition to the mainstream of his local school. The exact level of Shane's disabilities cannot yet be accurately assessed. But it appears that the notion of placing him in a regular grade one, that is within the mainstream of his school, is not a new idea to the school personnel. They seem very supportive of Sara and interested in welcoming Shane to grade one.

As an educator, I was particularly moved by the different responses the schools have made to these three children. Bruce is now having a very difficult time, though conflict was not so much a part of earlier schooling experiences. The situation has now deteriorated to the point that unpaid professionals (family friends) are currently trying to mediate between the family and the school. They are trying to establish a more appropriate school program for Bruce, one which capitalizes on Bruce's social learning skills. Marianne's experiences have been consistently more positive, mostly because of a very responsive grade one teacher and because of Anne's skills in working around administrative disinterest, and her continued monitoring of the situation. After Sara's struggle to get Shane included in early intervention services, Shane has experienced the most positive educational services, and is being welcomed into his neighborhood school for grade one.

These differences in experience may be partly due to differences in the children's disabilities, and to the different ages of the children. Part may be due to different educational philosophies of professionals working with young children as compared to those of professionals working with older children and adults. Part may be due to personal differences among these professionals, or to differences in parental attitudes and behaviours. It is difficult to explain these differences with any assurance of accuracy.

I feel certain, however, that some educators will explain the differences almost totally in terms of differences in parental attitudes, particularly associating negative behaviours with

Bruce's parents. And yet, in interviews with all the mothers, and family discussions with all the families, I noticed no hostility or irrationality in Bruce's parents, or in the other parents in the study. All the parents were calm, rational, cognizant of their situation. All were planning for the future and had developed strategies to get the services that they wanted.

However, I did notice that Bruce's parents are more tired than the other parents, and more tired of the battle. It is more likely that the schools have worn down Bruce's parents more effectively than the other parents. Of course, there has been a longer opportunity for this to be accomplished. In addition, there seems to have been a genuine change in the attitudes of schools over the time period defined by the different ages of these children. Many children and their parents have challenged the schools, over the years, to provide appropriate schooling that will help children with disabilities remain in the mainstream of life, as independently as possible, for as long as possible. One is grateful for this change in the attitude of school personnel and for the incredible amount of parental time and energy that went into effecting this change. At the same time, one also wonders about the children, like Bruce, and about their parents. Are there going to be enough changes to bring more opportunity and better quality of life for them, in time for them to enjoy such change?

4. Daily Living

a) struggles

Most, but not all, of the struggles specifically associated with their children's disabilities, that these families face in their daily lives have to do with education, health care, or other developmental needs. There are some struggles, as well, associated with trying to find adequate information about each child's disability and trying to find optimistic possibilities for each child's future. I was deeply moved by the level of involvement and the time and energy expended by these parents in the daily effort to get services, find friendships, provide interesting mainstream activities and a high quality of family life. In Bruce's family, these tasks were done in concert by both parents more than in the other two families. Because of employment demands, Marianne's and Shane's families had a more alternating style of sharing responsibilities. All three families, of course, spent varying amounts of time together as a family group and carried out responsibilities jointly during those times. As a society, we need to acknowledge that families with one disabled member have to cope with many extraordinary demands and have to work hard to get the services that rightfully belong to their children. It is very likely that they are doing these things in isolation, with little daily assistance to meet the complex demands of their lives.

b) needs

Martha, Anne and Sara expressed a wide range of needs during the course of our interviews, including many common needs. All three mothers indicate that they could use some tangible support and respite, in addition to emotional and verbal support. Anne and Sara state that they would value an opportunity to express how they feel in the presence of people who would understand. They also indicate a desire to talk with other parents of disabled children to share their daily challenges as well as their feelings. All three indicate a need for accurate information and some shared advocacy with people who do not face these struggles on a day-to-day basis. Anne was particularly eloquent about needing some materials that would inform and also lift their spirits and Martha spoke carefully and meaningfully about the need for others to share in the advocacy. Parents have too much to do and should not be expected to do all of the advocacy work, too. All three indicate a need to work outside the home as a break from their family demands and as an opportunity to be present and functioning in the adult world. Sara, and to a certain extent Anne, indicate a need to resolve personal barriers associated with the disabilities and early illnesses of their children. Sara is especially touching in her expression of a need to talk about her feelings concerning her son's disabilities. All three indicate a need to fulfil their own personal needs as individual human beings, apart from being mothers and managers of households. Lastly, Martha poignantly expresses a need not to be exploited by a system which does not adequately recognize the contribution to society as a whole (and saved tax dollars) which care-givers of disabled adults provide. There were so many needs expressed that I feel inadequate to address all of them. Some have already been discussed in other sections of this report. I would like to focus here on two needs: the need for accurate information about their children's disability, and the need to have a safe place to discuss their situation with people who would understand.

Finding good and useful resources is important. Reading materials and videos of children with disabilities, clearly written and with enough information about the disability to make attending to the material worth a parent's time, need to be developed and need to become more available. Parents are not lacking in intelligence and they are not looking for only reassurance. At the same time, they certainly are not looking for educational materials which are going to overwhelm them or destroy their hopes. Most parents have a good idea of what their children can and cannot do and have a good understanding of their children's learning abilities and style. A good reference list of materials that are available and where to borrow them, plus more materials that will lift parents' spirits, while giving them appropriate well-organized information would be useful and appreciated by parents. Children with disabilities live every day with parents, most of whom are trying their very best to do a good job. General descriptions of children's developmental stages and the developmental tasks of these stages could be readily available to parents. Along with these, there could be made available well-written surveys of "best practices" for helping their children to grow and develop to their very best potential. Child disability should not be shrouded in mystery and lament. Among their rights, children with disabilities have a right to have their lives celebrated and a right to the best possible opportunities for development. Professionals have the power to share information and to join parents in celebrating their children's lives.

Ongoing support for parents of children with disabilities is a very important need. Anne was instrumental in establishing a wonderful support group which met every week in the local hospital's therapeutic pool. What a good idea! The children play and swim and the parents watch the children and talk to each other. They share complaints and frustrations and they also share strategies and successes. They support each other and give each other a break, as well. While not every support group can enjoy the "warm tub" while supporting each other, a regular opportunity to talk and share and relieve tension *apart from advocacy responsibilities* seems to be a must for parents. I think this would be a valuable asset for all parents, and even more necessary for parents of children with disabilities. The mothers in this study definitely expressed a need to talk and to share. Meeting this need would not be very difficult. This could be a regular service provided by advocacy groups. On the other hand, there is no reason why other agencies (service groups? churches? hospitals?) couldn't regard the providing of a room -- perhaps some coffee or tea and some initial organizational leadership, maybe some longtime administrative work, like telephone lists and telephoning, perhaps providing some transportation -- as part of their service or ministry or outreach. This parental need could be easily met. What is required is a person in every community to initiate some activity, and a community will to support families and their children.

c) changes that bring hope

In the lives of each of these families there are reasons to be hopeful. Positive changes are probably more abundant for the younger children, but it is possible to see hopeful happenings in Bruce's life as well. These hopeful signs lift the spirits of each child's mother. It is easy to talk to parents about what their children cannot do or how their children fail. What is a little more difficult is to find all those things that a child is doing better than before, to find out how a child learns so as to capitalize on that factor, and to figure out ways to help the future look brighter for these children. Anyone can talk about all the "nots". What makes professionals worth their salaries is the ability to find what the child can do and to help the child build on that, and to increase the number of things that the child can do so as to increase the child's competence in complex ways. At the same time, professionals worth the money continually give parents hope and meaning and continually support parents in the many good thing that they are doing. The mothers in this study all gave examples of things that they see happening that give them hope. Each has found at least one professional that she thinks is working well with her child and each can point to growth in her child. As professionals, we would be wise to take very seriously the descriptions of positive interactions with professionals that these mothers have experienced. We can learn from both the mothers and the professionals. I am thinking of the medical doctors that have behaved sensitively and compassionately toward these woman and their children; the speech therapist who brought the process of language acquisition alive for Sara; the grade one teacher who learned from a little child (Marianne) not to make limiting assumptions about her; the beginning teacher, still in pre-service training, who learned to "read" Bruce and used her "reading" skills to teach things to Bruce that he found exciting and satisfying; the professional(and friend) who volunteered to initiate the Circle of Friends for Bruce and the professional (and friend) who volunteered to act as a "go-between" for Martha and David in the communication between family and school. Of course, we cannot forget the wonderful friends and neighbors, the teen-agers in Bruce's Circle of Friends, and the extended family members who are beginning to offer some "hands on" support to Shane. These eamples and many others have made a difference in the quality of life for Bruce, Marianne, and Shane. We have much to learn from them. Our textbooks and professional societies are limited; professional growth and development must also take place through our involvement in the lives of our clients and their families. They have much to teach us.

d) strategies

These mothers are problem-solvers. They have identified many strategies to help their children to develop, to enter the mainstream of life and to help themselves survive the demands put on them. While I was delighted to see the planning and coping skills and the capacities for adaptation that these mothers possess, I could not help but wonder, with people getting paid to provide services, why does the provision of appropriate services require so much parental strategizing, initiating, monitoring; in short, why does this require so much parental time and energy? If parents are labelled "nags" or are a "problem", maybe it is because we professionals have forced them into these behaviours because we are not doing our jobs. Of course, not all professionals are guilty, as the many positive comments about professionals and their work made by these mothers attest. But the questions remain, why should parents have to be strategists at all? Why should they have to initiate? Why should they have to monitor?

e) growth

Like all families, these families have experienced growth and insights about themselves as individuals and as families. None would have wished to have a child with disabilities, but all three mothers and all three families have taken the daily encounters of this challenge as an opportunity for growth. The situations of these families have put additional demands on siblings and the siblings are responding very well. This is particularly true of Marianne's brothers and Shane's sister. Bruce's siblings have not lived in the same household as Bruce, except for the very earliest years of Bruce's life. Bruce's parents, however are pleased to see that now these adult children, especially one of them, are seeing Bruce in a new light. They hope for continued growth and understanding and expect to see this develop as Bruce's older brothers have more and more opportunities to interact with Bruce.

f) parents and professionals

During the course of our discussions, each mother articulated ideas of how the relationships between parents and professionals could be improved. For the best development of the child, no matter what the child's disabilities, parents and professionals need to work as a partnership. Communication has to be open and honest and meaningful. Each party should assume the best possible motives and the best possible interests in the child on the part of the other, unless there is definite reason to assume otherwise. These parents want professionals to display a definite interest in their children with disabilities and to assume genuine professional responsibility for them. For their children they have the goals of independence, as much as possible, and life in the mainstream, as much as possible. These parents know their children and they want their knowledge acknowledged, respected, and incorporated into the decision-making which affects their children's lives. These parents want their children to be seen as whole human beings, no matter what the child's limitations. And they want professionals and other service providers to see their children and work with their children within the context of the whole family. These requests read like a litany of the "best practices" for working with children and their families (Johnson, 1989). There is nothing here that is beyond what can be reasonably expected of professionals and other service providers at the present time.

g) satisfactions

Martha, Anne, and Sara, while freely discussing the stresses, anxieties, demands, and complications of family life when one child in the family is disabled, also indicate in many ways the satisfactions which have resulted from each family's challenge. More striking than any individual comment, however, is the air of confidence and competence that these families present. Yes, they get tired; yes, they have had to make specific adaptations, in varying degrees; yes, they have faced many struggles, which are not over. Nevertheless, each mother can express satisfaction with her own experience and in the knowledge that their families are meeting the challenges that child disability presents. Having a child with disabilities has provided its own opportunities and satisfactions to be celebrated. I think they would like to share this celebration with a larger circle of people -- friends, school, the community, but they are frustrated in this regard. Many people can't seem to find much to celebrate here, even those whose training, would appear to give them cause for celebration.

Questionnaire Data

Data were gathered from both mothers and fathers of the three study families using questionnaires from the work of Carl Dunst and his colleagues (Dunst, Trivette and Deal, 1988). Questionnaire responses were analyzed and all analyses were discussed with each couple. This data-gathering activity provided an opportunity for the fathers to give information to the study and the ensuing discussion provided time for everyone to clarify or give additional information. In general, the couples agreed with subsequent analyses and the information from the questionnaires and discussions supported the interview data previously provided by the mothers. Any reported differences between families should not be interpreted as indicative of one family's "superiority" over the other families in any given area. These questionnaires provide data that are descriptive of families and of their support systems. There are no "right" or "wrong" responses. Each questionnaire is discussed in the same order as their presentation in appendix C.

1. Family Functioning Style

Questionnaire responses and parental interactions during observed family discussions indicate that each couple functions as a partnership in creating their well functioning families. While there are differences in style and differences in situations, all the study parents provide a family atmosphere that is loving and caring for themselves and for their children. All three couples indicate a high degree of within-couple similarity of response to questionnaire items and to the listing of family strengths. All three couples indicate the presence of considerable cohesiveness in each of their families, though this is more clear with the oldest couple (Martha and David) and less clear with the youngest couple (Sara and Phillip). At the same time, all the parents except Sara indicate difficulty in going outside the family for help if it is needed. It is not clear whether this attitude exists because the families are unwilling to seek help or because they do not perceive the possibility of help outside the family. The latter is the more likely explanation. Certainly Sara has been the only one of the parents that has found any significant personal support outside the family circle. Martha and David, as well as Anne and Sam, mostly find their support from each other. All three couples solve their problems primarily by themselves, with Sara being the exception, once again. She finds support for her concerns, from her husband and from outside of the home, when she needs it.

2. Family Needs

David and Martha, and Sara and Phillip showed quite a bit of within-couple difference on this questionnaire; Anne and Sam's responses are more similar. Both David and Phillip left many questions unanswered or "non-applicable," but so did all six of these parents, in varying degrees. In general, they indicate a moderate level of needs. In every case, the mothers indicate more needs than the fathers and a higher level of need. This is especially true for Sara as compared to Phillip, though Phillip expresses some needs, as well. The failure to respond to some items is probably partly a true indication of no need, partly an indication of each family's (rightful) pride in solving their own problems, and partly due to our socialization practices. These inform us early in our lives that it is more acceptable for females to indicate a need for help than it is for males. Differences in each family's stage of their family life cycle probably explain a good portion of the expressed needs, as well. It is quite clear, however, that these families are handling their problems and are finding ways to meet their needs. There is considerable support within each couple's relationship. Each person indicated "spouse" and the most constant and reliable support.

3. Family Resources

David and Martha indicate "non-applicable" for many items, but Anne and Sam, and Sara and Phillip answer most of the items.

There is considerable agreement within each of the two older couples, while the youngest couple, Sara and Phillip indicate many different concerns. David and Martha show more concerns about time than concerns about money. This was not true for the two younger couples, whose concerns cover both time and money. In general, the mothers articulate more concerns than the fathers and their concerns cover more areas, including concerns about resources to help them meet their own personal needs and many concerns about finding enough time for family, friends and spouses. The variations in concerns regarding time and money probably reflect the different stages in the family's life cycle in which each family finds itself. Differences between the mothers and the fathers probably reflect different roles and responsibilities within the family, as well as each parent's own socialization process and current social attitudes. These parents are trying to do what each has been socialized to believe is his/her responsibility as a parent. Because this study is focusing on family coping and family organization, in the light of child disability, it is not surprising that those parents traditionally responsible in these areas (the mothers) are showing many needs. What is surprising, is that these needs are showing so clearly, despite supportive husbands who help considerably in all areas of concern. It is clear to me that there is not enough support going into these homes from outside the families, and that societal attitudes which expect women and men, and mothers and fathers, to match very traditional roles continue. There is, as well, a lot of ignorance about what would be helpful for a family with a disabled child, or even about how to begin to help. We "outsiders" pull away, and assume that this is not our concern. It is *their* problem. Even people who have been paid to help these families have not always been helpful. On the whole, our society and professionals have not been consistently good resources for these families. No children are, nor should they be, solely the responsibility of their families.

4. Family Support

Parental responses to this scale support the discussion of the findings of the previous scale. While there is considerable within-couple agreement (after differences between Anne and Sam were clarified by discussion) members of all three couples indicate very little help and support comes into their homes from outside the family. As well, much of the help they are getting is not very helpful. Each indicates most support comes from the spouse. Bruce's parents and Marianne's parents articulate a feeling of "aloneness" both here, in responses to other questionnaires, and in the mothers' interviews. As has been previously seen, Sara indicates the most satisfaction with any support from outside the immediate family. In general, then, the youngest couple, or at least the mother in the youngest family has found the most support. This may reflect different levels of need, different individual personalities, different opportunities or different societal attitudes, over time. An adequate explanation of different perceptions of support on the part of these parents would likely have to include some portion of each of these possibilities. It is not clear why, but it is clear that these parents find very little support outside of their immediate family circle. They have learned to depend on their spouses and on their young children.

5. Personal Networks

All three sets of parents answered most of the items of this scale and each couple showed considerable within-couple agreement. While these parents see many people and have many contacts, few of these potential supporters from outside the immediate family are viewed as truly helpful. Extended family members have provided financial support if needed, but, with only a few exceptions, they are quite "removed" when it comes to providing "hands on" support to these families. Only Sara finds personal support from outside the family, which she integrates into her coping skills for meeting specific family needs. There are some "helping-professions" exceptions. Some medical personnel, notably those at Regional Centre, but also two of the three family physicians, provide very helpful services. Services provided by early intervention workers are regarded as a truly exceptional resource by two of these families. Both Marianne's and Shane's parents, especially their mothers, state early intervention services have been very supportive and very useful. It should be noted that only Marianne and Shane had the opportunity for early intervention (provided through their day cares). After some bad experiences with some speech therapists, all three families have become much more satisfied with the services in this area. This is primarily true of Marianne's and Shane's parents. Sara is especially pleased with current services in speech and language.

The information found in these responses verifies that found elsewhere. While some professional support is very helpful, much is not. Some is even detrimental because it takes up precious parental time and energy without supporting or helping, and some has been directly, even though unintentionally, hurtful. Somehow, we professionals have to become more sensitive to the effects of our "help." Our first rule for providing any kind of intervention service should be, "Do no harm." Similarly, we need to create ways of helping the general public and extended family members to grow in confidence about their ability to help. Every person in society is potentially a parent or an extended family member of a disabled child. General consciousness-raising and general learning about disabilities and their effects on children's development would have long-term positive effects on the social climate and future reception of children with disabilities as full members of our society. This is why the mainstreaming of special needs children is so important. Not only does it help children with disabilities, but it helps all those who then come in contact with them, to grow in ability to see more possibilities for them. We can grow to see them as part of the whole human family, with positive characteristics and talents as well as needs. When this is accomplished, the probability will increase that we professionals and society in general will be more supportive and helpful to the children and to their families, simply because the children are familiar to us. They are part of us and part of our presence. Most importantly, through greater awareness and more experience, we increase the probability that children with disabilities will be seen as children, and later as adults, who have rights. The most basic of their rights is that they be included *in*; that they be provided with opportunities to learn and develop to the greatest of their potential, sharing in a lifetime of interaction, as independently as possible, with everyone else and, being part of us, celebrating their lives along with all of us.

6. Social Support

Martha and David and Anne and Sam answered most of the items of this scale. Sara answered all the items and Phillip answered 14 of the 20 items of the scale. There was considerable agreement within couples on those items where both partners responded. Each marriage partner finds his or her spouse a big source of support and each parent indicates sources of support like friends and co-workers. All three couples have frequent contact with a fair number of persons outside of the immediate family, but few of their contacts are acknowledged as sources of support. David and Sam are more focused on their spouses as sources of support than are Martha and Anne. While they indicate David and Sam as primary sources of support, both see more possibilities of support outside of the family than do their husbands. Sam lists himself as a source of support, as does Sara. In addition, Sam's sources of support, apart from Anne, appear to be rather "serious" types of individuals. It would seem that both Sara and Phillip see sources of support outside the immediate family.

Anne, Sam, and Sara see their children less accepted by these outside sources of support than do Martha, David and Phillip. That is, Martha and David agree that Bruce is widely accepted among the sources of support they have indicated. Anne and Sam agree that Marianne is narrowly accepted, primarily by close family members and friends. Sara and Phillip do not have the same perceptions about Shane's acceptance within their sphere of social support. Sara feels he is accepted, only by the immediate family regardless of how he behaves, and Phillip feels he is accepted by almost everyone within their sphere of social support. Whatever the individual perceptions, there is a lot of room for more support and acceptance, here. There is a lot more that service agencies and society, in general, could be doing to help these children grow to adulthood. We readily accept that typical children need many different adult models and social contacts in order to develop optimally. These children are no different. They need more than their families, especially as they mature, and their parents need some periods of freedom from parental responsibilities.

7. Support Functions

David answered fifteen of the twenty items of this scale, while the other parents answered all of the items. For the items that both partners answered, Anne and Sam indicated considerable agreement and both Martha and David, and Sara and Phillip indicated about 60% agreement. All of the mothers responded in ways which showed more needs, and more personal needs, than the fathers. They want someone to talk to about child rearing, someone who is having similar experiences. This information confirms what was said in their interviews. They also want some guidance in finding information and services that would be helpful for their children. In general, the fathers indicated fewer needs overall and fewer personal needs.

It is interesting to note, that David checked that he needed "someone to relax or joke with" (item # 14). In reviewing Sam's listing of contacts outside the home, it seemed to me that there was a scarcity of informal and "fun-generating" contacts for Sam outside of the home. Both David and Sam seem to be indicating a scarcity of non-serious companions and opportunities to play. The fathers in this study take their family responsibilities very seriously. They "spell" their wives often in child care and domestic chores, in addition to their traditional responsibility of earning the family income. Because of the additional time and energy demands on these families which arise out of the special needs of their disabled children, there is not much time left for recreative fun. This is a serious lack for these families, not just for the fathers. There is very little opportunity for these parents to *re-create* themselves. Anne probably comes the closest to achieving a balance of responsibility and fun. She has her swimming "support group", her regular "crafts night", and regular walks with a neighbour. Sara comes close to achieving a balance, though she continues to express a need in this area. She has her two twelve-step programs and their occasional after-meeting social ventures, her sister as confidant, and her somewhat regular Saturday afternoon crafts. Phillip has friends with whom he socializes, although sometimes this presents problems for the family. Martha and David mostly have fun at home, but both indicate a question about "balance" in their lives. These parents, with the qualified exception of Anne and Sara, mostly "soldier on" in relative isolation, finding fun where they can, and *if* they have time for it. Along with the very real demands of their lives, this is a perfect recipe for emotional "burn-out". I've seen it happen too many times. Families carry on for years, meeting the demands of their lives, going to meetings, going to doctor's appointments, interacting with the schools, doing what they are supposed to do, and then everything falls apart. I am not saying that disaster is inevitable for the three families of this study, but that there is a risk here, and few "outsiders," especially few professional "outsiders," are doing anything to even acknowledge the risk, let alone to minimize it. It is almost as if we professionals and society are saying, "This is your child and your responsibility. We will assist you in ways that we will define, and we don't intend to give you too much. Moreover, in order to show us that you deserve it, you will have to work to get whatever it is you think you need." This certainly describes what Bruce's parents have had to face, especially since Bruce turned 18. There is almost a "grudge" against Bruce's being home, rather than in an institution. The parents of the younger children have met a less grudging atmosphere. These attitudes exist, despite the fact that we know children reared at home, whatever their levels of competence, perform better and are happier and more socially appropriate than those reared in institutions. Moreover, this is accomplished with the spending of far fewer tax dollars, because parents devote much time and energy to helping their children grow, develop, and learn. There is almost no acknowledgement of this parental contribution, certainly not at the policy level. These children are the responsibility of all of society, yet we let their parents exhaust themselves, time after time. We give them only marginal support, despite the taxes they save us and the better functioning citizens they present to society when the child-rearing years are over.

8. Projects

All three sets of parents indicate specific "projects" that they would like to accomplish. The projects include both family goals and personal goals, but all include some projects for their children with disabilities. The projects are very concrete and include ideas about who could help the family meet their project goals. Some specific projects are as follows:

Bruce

-childcare (employment related)

-Circle of Friends

Marianne

-computer time

-speech/alternate communication

-making new friends/recreation

Shane

-toilet training

-speech and language training

These goals are very appropriate for the children. Sources of support are listed by each parent, and consist mostly of people who have been supportive in the past. The circles of support for each of these families need to be widened. While everyone is grateful to the people who have provided support in the past, new people need to be added, so as not to wear out these children's welcome and to help to share the support required among a larger number of helpers. There are *lots* of people out there; there are very few children (relatively) with these kinds of special needs. Somehow we have to help people know that they have the skills necessary to give support (ordinary parents do these things routinely) and that their support would be welcome.

MAPS Data

It seemed that the MAPS planning session was useful and helpful for these families, even for Bruce's family, which has had several planning session like this over Bruce's lifetime. Planning like this helps parents to focus and articulate their concerns and it provides a specific time for families to communicate what they are thinking. In the case of this study, the inclusion of some educational personnel for Bruce's and Shane's planning session proved to be very helpful to the planning process and to the parents personally. For Marianne's planning session, her two older brothers were included. They added an important dimension to the planning and it provided an important opportunity for the boys to develop their thinking about some issues related to their sister's disabilities and to express themselves, to the extent that they wished.

Each family history and the history of each child in the study has unique features, yet there are many things that these families have in common. All speak of the period of adjustment each family went through at the time of each child's birth or return to the family. All three families coped with very serious illnesses with Bruce, Marianne and Shane. This continues to be a serious concern for Bruce's and Shane's families. All speak of continuing the struggle to get information and adequate services for their children. All restat, as well, the rewards and satisfactions for the families and for individual family members; the opportunities for growth; and the development of new skills. These families have learned to do things that they never thought would have been possible. While the experience is demanding, and they get very tired, having a child with disabilities in their families has had its positive and rewarding side, too. But all three speak of needing some help and support that they are not getting.

Each family dreams of as much independence as possible for their children and as much support as is necessary to help these children remain in the mainstream of life. They hope for the development of functional communication skills, friendships, normal social networks, meaningful work, security, success, and happiness for their children. All see school as the basis of education and training for their children and the source of learning opportunities that will help their children have meaningful adult lives.

Their nightmares are the opposite of their dreams. Any kind of institutional living, even group homes, are part of the nightmare. They don't want to see their children without friends and without personal support and encouragement. The absence of these are the big factors which make institutional living a nightmare. They see, rightly, the loss of whatever has been accomplished, of skills and competence, of friends and caring, of rights and of human dignity. These are the fabric of their nightmares.

For these parents, and for many people currently in the children's lives, Bruce, Marianne, and Shane are real people with their own special learning problems, but also with their own special talents, gifts and strengths. Each child is unique and each child can learn. Each child requires, however, adaptations and accommodations on the part of others in order to learn and to function well in the mainstream of society. It is possible for them to learn and to function, but they, more so than children without special needs, have a certain dependency on others. They need others to go a little further to understand them, to teach them, to include them into the life that we all enjoy. It is very frustrating to have to be so dependent on the good will and cleverness of others.

When I listened to these families describe their ideal day for their children, I was impressed with how simple their wants are. They are not longing for unrealistic changes. They all want less time to have to be devoted on getting ready for school and more independence on their children's parts in getting to school. Bruce would dearly love to ride a school bus. Marianne is just about ready to walk home from school by herself. Shane will be riding a school bus, but the family is hoping that he won't have to be strapped into his seat, that he'll sit with a buddy as he is supposed to sit. They all hope for the schools to capitalize more on their children's ability to learn from their social experiences. They hope for growth in their children's ability to communicate something about their day's experiences. They want their children to be included in at least some of the usual age-appropriate activities. They would like to be much less directly involved in seeing that their children have these opportunities. They would like someone in the lives of these children, other than themselves, who would do occasional special things with the children or see that they are included in some kind of a social life, some regular activities, and some spontaneous activities. They would like some of these social activities during the school week and some on the weekends. In short, they want more "normal" age-appropriate experiences for their children and the recognition of how important these kinds of experiences are to Bruce's, Marianne's and Shane's growth and development.

Observations

I visited with each of these families several times. I saw each mother alone on two occasions for lengthy interviews; I met with each couple on two occasions and facilitated a planning session with each family; I saw two of these families at community events. They always presented themselves as loving, caring couples working together to carry out their family responsibilities. I continue to be impressed with the stamina of these parents and their competence in meeting the demands and challenges of their families, and their children with special needs. I am also aware of their fatigue and their sense of isolation. These can be observed in their words and by their behaviours. The couples in this study help each other out and pick themselves up after each set-back. Then they start again. The children themselves are not as demanding as is the challenge of getting services to meet the children's special needs. One doesn't have to be a particularly astute observer to know that these parents cannot go on meeting all these demands indefinitely. They are pursuing important goals: helping their children to become as independent as possible and helping their children to be, as much as possible, involved in and learning from culturally normative experiences.

Limitations of the Study

Qualitative research is different from quantitative research in several specific ways. Each type of research has its place. This study attempted to discover the meaning-making (Guba and Lincoln, 1982) of the co-researchers' experiences of having a child with disabilities. It is an attempt to understand their world from their descriptions of it. It is inevitable that the researcher and the co-researchers would interact with each other in order to gather the data of this study. It is acknowledged that in interacting we influenced each other in ways associated with the research question of this study. Data from the questionnaires, which add a dimension of information beyond interviews and discussions, however, guard against a distortion resulting from these interactions. Generalizations beyond these three families are neither possible nor desirable. This study is about the families of Bruce, Marianne and Shane. Whether or not their experience is more universal remains to be determined from future research based on a large sample of parents. But generalizations can be made about what would make the lives of these three families more like their counterparts who do not have children with disabilities. The research methodology of this study is used to ask the question, "What is happening here?" (Stainback and Stainback, 1988). I believe it is possible to answer this question from the data of this study.

General implications

General implications need to be discussed at the societal level and at the level of professional involvement. We need a general attitude change which acknowledges that these disabled children are our children as much as any other child. They are part of us. Disability is part of the normal risks of human existence. It is normal that not everyone will be born perfectly formed or remain perfect throughout a lifetime. Unless we are prepared to eliminate disabled people, as was done in other times, both ancient and not so long ago, we must be prepared to help disabled people to live among us. We must be truly prepared to help them become as competent as possible and to enjoy inclusion, as much as possible, in our corporate life.

It follows that those who are in the helping professions who are called upon to help in situations where disability exists must do just that. We must help and we must do it with an attitude of warmth and acceptance and above all with the attitude that people with disabilities are a part of the normal spectrum of humanity. We must not help out of a sense of pity or as a favour. We help because it is our job. We are *paid* to help because we have knowledge and skills that are of value to the optimum development and quality of life of the clients who come to us. People with disabilities are a part of the normal spectrum of clients that we will see. They are our responsibility as much as any other clients.

Acknowledging the enormous contribution of parents both for the development of their children with disabilities and for their role in educating the rest of us, will help all of us to see parents of children with disabilities as sources of information and experience, especially about their own children. Acknowledging the contribution of parents will help us to see them as partners in planning and decision-making. They are our richest resource for whatever professional plans we might have, both in shaping the plans and in implementing them. We ignore parents at our peril. We will do a much better job as professionals if we include parents as full partners in whatever we are doing with their children. Moreover, by acknowledging parental competence and knowledge, and by working *with* parents, we can decrease the time and energy that these already over-worked parents must expend in getting the services that rightfully belong to their children. A relationship of mutuality and equality will go a long way in minimizing what is the great shame of the findings of this study, namely, the inordinate amount of time and energy these parents must expend to get what their children deserve.

Implications for Service Providers

The attitude change stated above is critical to appropriate providing of services. Following this, real hands-on types of assistance are required. We hope, as more and more children with special needs live and grow and develop at home and at each neighborhood school, that more and more acts of support will evolve out of the normal day to day interactions of people. Neighbors will lose their self-consciousness and fear of the unknown and more and more models of support will evolve. As well, service providers will anticipate what will be needed. Anticipation and planning is a must. We know who these children are. We know what will be needed as children with special needs mature and develop. It should not be the responsibility of parents to have to raise children *and* develop community services. Working closely with parents in an atmosphere of mutual respect and equality will help professionals to discern what services are appropriate and to identify specific and appropriate service options. Parents have much to offer us here. Working together increases the probability that we can achieve the goal of independence, as much as possible, for these children when they achieve adulthood. Of course, providing support where total adult independence is lacking is society's responsibility and professionals are or should be the facilitators of this support. Where parents continue parental services, because of the nature of any given child's disabilities, they should be acknowledged and remunerated. Among other things, these parents are saving society a lot of money, and deserve recognition and some form of financial support.

Implications for Education

My primary identity is that of teacher. As a result I am particularly interested in the educational experiences of the children in this study and the families' responses to that experience. I was particularly gratified at the positive comments two of the mothers gave with regard to their children's early intervention experiences. It seems to me that we in education have a lot to learn from workers in day cares, early childhood, early intervention and the primary grades. We have a lot to learn about including all children and working with parents. It is true that things are very different at these early levels, as compared to the later grades, when schooling becomes very much more abstract and cognitive. Yet in every school, there are many times when even very disabled children can be included. Inclusion of all community members into many school or community activities needs to be viewed not only from the point of view of the education of the child with disabilities, but also from the point of view of the normally developing child (see Peck et al., 1990). It is a part of their education to learn about disabilities, and, in so learning, to learn about themselves. Moreover, unless there is a dramatic change in our ability to prevent disabilities, at least 10% of these normally developing children will be parents of a child with a disability. It is a part of our common human experience. Disabilities are a normal part of life. We fail in our goals to educate all children if we do not arrange the environment so that all children can learn about and learn to interact with all other kinds of children. We diminish future possibilities for all children.

Educators can do much to create positive receiving environments where all children can be included and where all children can have friends. Children with disabilities learn much in such environments, as do all children. We are social beings. All of us learn in very social ways. While some of us learn faster than others, all of us learn in relation to others. We learn social interactions, language, behaviours. We learn about our emotions. We model behaviours and we have fun together. None of us learns everything from books. All of us learn within a social context and we continue to capitalize on this throughout our lifetimes. People with disabilities are no different from the rest of us in terms of the importance of social learning for their growth and development. We would be better educators if we capitalized on this human characteristic more often. We would be especially better educators if we more often used and recognized the opportunities of the social environment as a resource to teach to all children, particularly those with disabilities.

Implications for Future Research

This study needs to be replicated with similar families in other areas of North America. We need to hear the stories of many parents. Similar studies need to be done, as well, with different types of families. What are the experiences of single-parent families, both those headed by women and those headed by men? What are the experiences of mothers who are not so articulate? not so supported by their husbands? of an ethic group not so similar to that of service professionals and school personnel? Equally important, a large-sample survey study needs to be completed in order to see how universal the experiences of these study parents is, compared to those of other North American parents. There are many possibilities.

RECOMMENDATIONS

1. Appropriate attitudes to adopt

-Societal

Disability is part of human existence. Some of us are born with disabilities; some of us become the parents of disabled children; some of us become disabled. It is a normal risk of life. People with disabilities, whether children or adults, are a part of us. We must be prepared to help disabled people live and work among us.

The parent who is the principal household organizer and caregiver is as valuable in contribution and expertise as is the parent who is the principal provider of economic resources for the household.

-Professionals

People with disabilities are a part of the normal spectrum of humanity. We are paid to help people because we have knowledge and skills that are of value for the optimum development and the quality of life of the clients who come to us. People with disabilities are our responsibility as much as any other clients.

Parents of disabled children are a rich resource of information and experience concerning their children. We will be most effective, as professionals, if we learn to work with parents and learn to include them into planning, goal-setting, and decision-making about their children.

Even though it is imperative that we work *with* parents, the responsibility for the development and monitoring of programs and services is ours. We know who the clients are and through planning with the parents, we know what services they need, now, and will need in the future. It is our responsibility to see that appropriate services are available without having to be "pressured" by parents. Parents have enough to do.

Our response to the parent who is the primary household organizer and caregiver should be as respectful and responsible as it is to the parent who is the principal provider of economic resources to the family. Similarly, we should be respectful and responsive to the parent who is the sole parent in any household. In all cases, we need to be mindful of the time and energy demands which parents face.

2 Policy

Because of the benefits to both those with disabilities and those free from disabilities, life in the mainstream is the option of choice, as much as possible, for all human activities.

Financial equity must be pursued in order to minimize the differences between natural and adoptive parents' financial risks when parenting a child with disabilities as compared to foster parents' risks. This is especially important with reference to natural and adoptive parents who care for an adult child.

Provisions for more respite care, especially in the client's home, more direct support in meeting the daily needs of clients, and more specific support in meeting the social and recreational needs of children and adults with disabilities are desperately needed.

Provisions for adequate, affordable, and reliable child care as an option for families, is basic to any kind of equity in quality of life for all parents. This is especially important for parents of children with disabilities, some of whom require specific kinds of child care for much longer periods of time, than do children without disabilities.

3. Service Providers

Work *with* parents, valuing them and their contributions and ideas; acknowledge their expertise.

Start with the positive. Celebrate the child and her competency. Only then, move into the child's areas of need and how parents and service providers can help the child.

Don't overwhelm parents; don't dishearten parents. They are aware of the child's limitations. Provide information and ask parents about what they know; what they think. Focus on two or three achievable goals. Support parents. Try to see the situation from the point of view of the family. Look at the whole child and look at him within the context of his family. See the child first and then look at the disability.

Try to appreciate what it means to be responsible for the child's care twenty-four hours a day, seven days a week. Contemplate alternatives. Would the child *really* be better off? All indications assure us that children grow and develop best at home. Give parents a hand.

When parents are asked to work on skill development, elect skills that are truly appropriate and useful and which makes sense to the child. Ask the parents, "Would it be possible to work on this? Do you have the time? Will it work into your family's schedule? Would acquiring the skill be helpful and useful?" Ask parents to provide feedback on the process. Don't be afraid to admit error. Do be willing to rewrite the plan. If the child fails, ask, "Could there be reasons for failure other than simply parental disinterest, incompetence, or neglect?"

When planning programming and making professional suggestions ask, "How can we use this family's strengths? How can we avoid making any family member feel left out? What information and supports have to be in place in order to avoid failure, and especially, in order to avoid disaster?"

Be prepared to change "the system," or the school, or the classroom, or whatever, to meet the child's needs; do not expect the child to make adaptations to fit into what "the system," or the school, or the classroom, currently has to offer.

EPILOGUE

This study has been a very important experience for me. I feel especially grateful to the University of Saskatchewan for providing me with a sabbatical leave to gather the data. Time to do research is a very critical component in any academic career. Because of the enormous amount of data, time has been a particularly important ingredient for the completion of this project. Similarly, what would any research be without the subjects; or as is the case here, the co-researchers, who spent much time and energy in telling their stories? Here we go again. Parents are spending time and energy to help a professional. It's supposed to be the other way around. Let us hope that the information from the lives of these families goes beyond a mere final report of the study. There is too much at stake here. I am certainly committed to a wide range of dissemination of these families' knowledge. They took part in the study hoping that it would help to achieve a better quality of life for future children with special needs and their families, and perhaps for their own children and families. Now it's up to us who earn our livings working with people with disabilities, to read, think, and reflect; and then to make the necessary changes in our services and the manner in which we provide them. Have we got as much commitment and stamina as these families? I live in hope.

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APPENDIX A

General Interview Questions

INTERVIEW QUESTIONS

Interview # 1 (Tell me what I need to know.)

- Tell me something about the "history" of your family and of ____________'s disability.
- Tell me something about the characteristics of your child. Be sure to include both positive and negative characteristics.
- Tell me some of the characteristics of other family members, especially as they relate to ___________.
- Which characteristics of your child are particularly stressful or difficult to manage? How do you respond to these? How does your family respond to these?
- What are some coping strategies that you have found useful in your family? (passive appraisal, reframing, inner strength, social support, professional support, whatever...)
- Tell me about your family's strengths.
- What people or agencies provide any kind of support for your family?
- On a scale from 1 to 10, how would you rate yourself on "inner strength"? What about other family members and their "inner strength"?
- On a scale of 1 to 10, how would you rate yourself on knowledge about your child's disability? Tell me about some of the features of your knowledge. What about other family members?

- Tell me about how your family participates in your child's education.

Interview #2 (Follow-up of first interview, and "personal" questions)

- Individualized questions based on previous interview, designed to get more information or to clarify, were asked at the beginning of each second interview.
- Tell me about how you feel about yourself... Are you satisfied with your life? Do you feel you are a competent person/mother? What are your hopes for the future for yourself? What do you do to take good "care" of yourself?
- Tell me about your job. What is your job. Do you do it well? Are you satisfied with your job? What about the people you work with...are they good to work with?
- All families have problems and conflicts from time to time. How do you feel about your family's ability to deal with its problems? How does your family deal with it's need to communicate effectively?
- What do you do for FUN? How do you recreate yourself?
- Tell me about your friendship net-work. Are you satisfied with it? Do you feel "supported" by your friends?
- What things make your life stressful? How do you manage these?

- What do you do in your life that is not your usual "work" but isn't exactly "fun", leisure, or recreation? Is this satisfying? (altruistic, religious, political, whatever).

APPENDIX B

Categorized Interview data (#1, #2 and #3)

CHILD

Child's Characteristics

He is a people person. He is a real socialite. I also find him to be quite perceptive in his ability to know whether people warm up to him or they don't. What else can I tell you about him? He is super active.

Any time he cries .. he cried yesterday for the first time in months because he was hungry... He cries for reasons. He never just cries for anything that we can't figure out why.

Communication

We know him. We just sort of know. The focus of all of his priorities (home, school, everywhere) is all on pre-language kinds of things. We are constantly offering him choices about everything. We have consulted a lot with specialist in Regional Center who taught us how to work with Bruce around making choices, teaching him some of the very basic developmental skills around cause and effect and learning to find things that you hide and all of that stuff. Once we started doing that, he became more able to express himself. If he doesn't want to do something he just physically will not allow you to force him to do it. He has his ways of saying "no" and he is learning to push things away when he doesn't want something and ...

There is a lot of eye pointing and stuff, so you really have to be able to clue into Bruce. He will fix onto something that he wants with his eyes. He breathes really heavy and his eyes get nice and wide open and bright and ..

I have a couple of friends who spend time here and they can "read" him. He has a Circle of Friends and they know him real well. They are real good at "reading" Bruce.

I know that Bruce is severely mentally handicapped and I don't think either one of us has tried to deny that, but I think that his inability or our inability to figure out a way to get him to communicate has really held Bruce back a lot. You always get the sense from him, once you get to know him, that there is a whole lot going on in there that just isn't coming out... Because we have not found a way to help him get it out.

Imagine not being able to communicate

Well we were late in getting supper and Bruce was sitting and all of a sudden he started to cry and we said "Bruce, are you hungry?" and he went (smack, smack, smack).

I guess one of the big things, is if Bruce could communicate, could he tell us things like, "I'm uncomfortable and I need to go to the bathroom"; would, all of a sudden toilet training not be such a big issue for us anymore? Or even the visits... Bruce's friends are about as good as "reading" Bruce as we are... But if they come by, you can't read "What did you do yesterday Bruce?" and he can't initiate any contacts with them.

Parental struggles to communicate

So we have had to spend a lot of time just sort of being taught that these behaviors mean things. They really mean things and that people just don't do things for no reason. So to get to know what things mean and tell Bruce that we know and give him what we think he is looking for sort of thing. And it has really changed his life. Even that little bit has turned him right around. He has become more outgoing and more assertive.

Child's play, pleasure, recreation

He is into things like playing with cupboard doors and rolling things off ends of counters and seeing where they go and what happens to them. He's quite an explorer in his play. He does a lot of play kinds of things. He does a lot of roaming around. He plays a lot with his dad. They sort of rough house and carry on.

If there is just David and Bruce here at home or just Bruce and I here at home he is a little more subdued. When all three of us get home from work and school (lately they have been home before me) when we are all home together, there is an instant change in Bruce. All of a sudden he is more lively, happier. He is clapping and laughing and carrying on and he seems to like the time around supper when everybody comes home. It is a good time for Bruce. He really enjoys that.

A lot of games we started playing around, you know, just sort of functional cause and effect things have made things a bit crazy around the house. He is constantly turning the dishwasher on and he is, you know, switching on and off the lights on us and all this stuff and running to flush the toilet and turning on taps. But it's neat stuff so I guess it is nice to be busy in that way with him versus some other way that is maybe less productive for him.

"Knowing"/learning

He has a really good memory. He knows things. David is a bag-piper so whenever the bag pipe comes out, Bruce is heavy breathing. He's all over his dad and he knows. He's trying to get the case open and he just knows that the pipes are going to be played. He is crazy about them.

No, the kids actually teach Bruce things. He learns from them. Kids get up, they want to sit on their desks and put their feet on the chair. Well, so does Bruce. It's so neat.

He wants to please. He wants to know he's done well. He looks to be told he's done well. I think a lot of people don't even recognize that he's looking for your approval, when he's made something happen. A: He recognizes he just did something right. And B: he's looking for you to recognize it. And if you can't see that that's what he's doing, you don't recognize it. It's a lost opportunity right away... It's gone. And it's so sad because it's so critical for Bruce.

Child's friends

Bruce met them at the Junior High at Grade 8 level towards the end. Bruce had a lifestyle plan in the middle of his grade 8 year or early in his grade 8 year. The over-riding issue was that Bruce was alone he had no friends. David and I were his best friends. We were his whole life and he was our whole life.

The first thing we had to do was to get him a little bit of time in a regular classroom so that kids could meet him, regular kids could just meet him and make a choice to see if they would like to become part of the Circle with him. It took us until about May of the following year before we could convince the school that Bruce had a right to be in a regular classroom. Just a homeroom, that's all we wanted - five minutes of homeroom to start.

Well, the Circle of Friends just took off. By the end of grade 8 school year, he had 12 or 15 kids who just rallied around him. And they started putting (in their own very special way) pressures on the system about if he's in homeroom why isn't he in this class? and why isn't he in that class? He ended up getting about half of his time into grade nine, Junior High level.

At this point in time, Bruce would be at the equivalent to grade 11 level right now. He's got about six really good friends.

When his friends call it is me they talk too. They want to know how he is doing and what he is wearing today and what he is doing friday night and so I have had to learn to talk to 16 - 17 year olds...

It has been real difficult for me because he can't pick up the phone and call them and they can't call him. But they are comfortable to call David or me.

One of Bruce's friends, Paul, said that for him, what he found so amazing was not only could he become Bruce's friend but that he could become our friend, that he had to become our friend and if he didn't like us it would have been very difficult to be friends with Bruce. That is really true, because of the level of Bruce's disability. So we have become a close knit little group. It's been really nice.

He's a real looker. He's got this one girl, one friend of his, that's probably his best friend. Her name is Marie. And I think Marie spends a lot of time thinking about Bruce... really a lot of deep thinking about Bruce. One time she said to me, "You know, if Bruce wasn't handicapped he'd have every girl in school." And he probably would.

When I look at Bruce before he had friends in his life and just take a quick snap shot of what his life was like before... it was not a pretty picture. His whole life revolved around David and I. He also just wasn't the same person that he is today. He wasn't as assertive. It just turned everything around. It's difficult to talk about it now. I used to be able to talk about it because it was so fresh. Life without friends was all we ever knew. That's really distant for us, at this point. He never went anywhere unless he went with us. You know, the focus of his social life was a trip to the K-Mart on Saturday mornings. And I'm serious about that. He never went anywhere.

For a while I experienced an awful lot of shock when Bruce first developed friends. There was a lot of not really believing or trusting. Because you'd go to these "Circle meetings" with these kids and they would say these wild and wonderful creative things. They got a real good picture of Bruce's life first of all. Mary went through a whole thing about who Bruce was and what life was like for Bruce, and drew some comparisons, she got the kids to look at: If their life looked like Bruce's how would they feel? And would Bruce feel any differently? Well they certainly didn't feel that he'd be feeling any differently, that he's probably pretty miserable and wishes things were different. So they were a perceptive bunch of kids as all kids, I think, are... probably more perceptive than most adults.

They started out being very focused around the school. They'd take him out at lunch or hang around with him after school, or "Maybe he could come to my house for a visit after school if you guys would pick him up?" Little steps like that started to happen. I remember after that started to take place, there was a bit of a non-belief or a lack of trust on our part that this was going to last, that these kids could really be friends with someone like Bruce. They really have that capacity to truly care. That is not some pity thing or volunteer work that they choose to do for a year and then let it go. Their relationship with Bruce is based on the fact that he's a person that they care about just like it would be for anybody else. That took some time for us. It took some time.

It just opened up a whole new world. He almost turned around instantly after being placed in a regular home room. It was like day and night and it happened real quick. All of a sudden he had some life and some spark and some.. a twinkle in his eye, that we never saw before. And honest to heavens it really just happened that fast.

Loss of child's friends

It's gotten messed up though, since the senior high, because here we've got the semester system. They don't have home rooms. We are finding it next to impossible to get Bruce into their classes.

If he lost all of his friends today we would simply be impelled to go out and start again. Because we couldn't deprive him of all the wonderful things that have ended up happening.

STRESS/ANXIETY

General parental stress

He is a very time consuming young man. He is very busy, I guess because of his seizures and with his neurological disorder he is ... His balance would be funny at certain times. He walks with a big gait and he could fall into things. You are kind of watching him a lot. You really never go and leave him alone in the room. There is just constant watching of him, mostly for safety sake.

All these sets of parents come to my mind. And you just see them doing it all the time, you know. Or one family in particular where the mom takes care of their daughters um..

all her medical needs and she's running up to meetings with doctors and taking care of all of that stuff. And Dad takes care of all the educational stuff and fighting with the school system, and they're running back and forth taking care of all of this stuff and not taking care of themselves.

David and I worked really hard to keep him busy on the weekends; but when you work, you know, it involves: What do we have to do that we can involve Bruce in? and then: Is there any time left over to do something that he might like? Like take him to the beach or take him for a drive or a walk to the park or...

I worry if something gets in the way of my being able to keep it all together. Because, as I said to you last night, sometimes it's like David and I are against everybody. And there's just the three of us.

I won't speak for David but I suspect that he will feel the same way... we're tired a lot. I don't know if people really know what that feels like.

And there's always this um, I'm not sure what the word is but it's like you're fighting against time. You feel that time is running out and things aren't getting done... you just feel really helpless to be able to get everything that you need. And it's not frivolous stuff. To us it's... He has rights that are not being awarded him.

Illness and stress

The neurologist's clinic, they come here every couple of months, they would see him and kept fooling around with drugs and medication. At that point he was on 6 different anti-convulsives. It had gotten to the point that nobody knew what was wrong with Bruce. Was i t - his seizures were totally out of control, which they were, but was that sort of based biologically or neurologically or his drugs because he was on so many. And the combinations... It had gotten to the point that you couldn't decipher what was really happening any more. I remember this past Christmas was just hell. I mean he was sick, he got to the point where he vomited constantly. He had diarrhea. He couldn't keep food down. He went from 103 lbs to about 80 lbs. It was just a mess. We got through Christmas. We missed a lot of work, a lot of work. I was grateful for where I worked.

So anyway, we struggled through it but I sort of felt that I wasn't anywhere doing anything for anybody, be it at work or at home. David was feeling the same. And we were getting lots of pressure from the school.

So anyway, he ended up in the hospital around Valentine's day. I had called the doctor. He wasn't any better and the doctor wanted me to try some new medication. I don't know what happened but he said to me on the phone let's try this and I just started to cry. I said, "I can't do it anymore, I cannot take that kind of responsibility because I am feeling that it was causing more harm to Bruce. I need more support than you over the telephone." So Dr. Curley arranged right away for Bruce to come to the Regional Center within three days and I had to go with him on the plane. He was so sick when we took him over. We couldn't both go because we couldn't afford to both go, either financially or to just manage, you know. Somebody had to work.

Anyway he was just so sick and he spent about 3 weeks in Regional Center and I kinda lived... I didn't live in but I stayed in Regional Center. I couldn't live in I just couldn't handle it. I was there from 9 in the morning until about 9 at night and then I left and had time to myself in the evening.

When we brought him home he looked reasonably stable for a while but he was only home for about a week when it all started again. We were just shattered all over again. We thought, oh my God what .. so he was only home for about 2 1/2 to three weeks.and he ended up back there again and he was there for 6 weeks.

If they'd just come and sit with him for a while and let me get away or whatever. Um, that would have been more support than calling me and asking me to go through all of the tests and all of the sickness and everything day after day. I found that really, really difficult to cope with. They never sent cards. Everybody else I know, all my friends, all Bruce's friends, all my family, all sent him cards. You know, get well cards. I don't know if they just didn't know if he would appreciate a card. I don't know what they think.

If we didn't have to worry about seizures, life would be wonderful. And people think I'm crazy when I say that but life is such hell when his seizures are out of control.

Stress (work/job)

But there was a lot of pressure that I was feeling about needing to have some answers about when Bruce was going to get better. All I wanted to do was get through a day.

Well to be perfectly honest, it really would have been nice to have somebody to come to me from my employment to say it's o.k.. We know that right now Bruce is more important than anything. I never got that once...

So I always walked around feeling guilty, and trying to justify x amount of time spent at work and x amount of time spent with Bruce. I would raise the subject every once in a while about that and it would be, it would not be as understanding as I hoped that it might have been. Um, it was more... well when do you think he's going to be better. When do you think you're going to be back.

It just would have been helpful to think I didn't have to worry about the work situation so much. Cause that really stressed me out.

Disability and stress (financial)

He's only on three medications now. He has one, which until the first of April was an investigational drug. Now it is on the market, and that is for his drop seizures and he is well under control with those. He is on Ativan which is a form of Depakene which controls sort of major/minor seizures and the Dilantin for his grand mal seizures. The only time he tends to seizure now is in his sleep. They are quite severe convulsions.

The phone bills to Regional Center were just atrocious, 200 to 300 dollars a month just to phone to Regional Center.

We get ours (diapers) from another province because they are cheaper. We have them shipped by courier every month. It works out cheaper to do it that way. But anyway I mean that the money for Bruce just doesn't go very far. But if he was in a room and board situation or in a group home or living in foster care somewhere, there would be a lot more money put into his keep. And it's not like we want to get paid to look after him. But there seems to be some kind of injustice here, in that we are just here twenty four hours a day for Bruce, basically free of charge to anybody. And somehow, at some point, you think this isn't right. Bruce is eighteen years old and if he didn't have a disability and he chose to live at home, it would probably cost him.

Demands on parents

Ya, they (parents of disabled children) have enough to do. They can't do any more. But we don't get a whole lot of support unless we're willing to get out there and fight and work for it.

The education coalition of which I am a member. It's a group... It's made up of parents of children from all the different disability groups... We just look at all issues around education and that sort of thing. It's kind of falling apart. At one time it did provide a bit of support but it was mostly a working kind of coalition to try to effect change. It was very busy looking at legislative things and policy stuff. But one of the things we have been doing for five years is running this summer program to try to maintain the kids skills. We deal with not just kids with mental handicaps, rather the whole gamut sort of thing. Any kids that are falling behind, if we can help hire university students... Of course, some of these kids learn more in that summer than may learn all year in school, because they get total one on one attention. So Bruce had a program half days for seven weeks in the summer. Part of it was computer and part of it was community. It might just be going to the park and taking his box of stuff that he's got there on the floor and just... We were teaching him to draw with markers and white boards. He fell in love with that activity... That he could make marks and wipe them off. So just doing fairly academic kinds of things but in new and different environments wherever we could find them. This young woman who's been with him for the past two years, just "reads" him like you wouldn't believe... She has picked up on "reading" his communications, no problem. And really came to care about Bruce. Studied in Regional Center and when Bruce was so sick she would come to visit him at hospital.

(Friends) stress from school

We almost get panic stricken at times because Bruce has only got a couple more years left in school. One of our arguments is that most kids keep and maintain their friends by their connections in school.

The pressure is on us, his parents to always be the ones to make sure that203ruce sees his friends after school, evenings, that sort of thing.

You don't make friends and maintain friendships with people that you don't see in school on a regular basis. That is the part that we struggle with the most in trying to get the school to see that they have a role to play.

Lack of support

There are Sunday meals at David's parents, every Sunday. It's sort of open to go down to be with the family. It's not always easy with Bruce just not feeling well. We go down and we would take Bruce and one of us would have to constantly sit with him. Nobody would say well let me sit with him for a while. I'll sit with him you know. Um, and it just got to be more work that it was worth. Bruce is much easier to care for here at home then at somebody else's home.

What hurts the most and really put a gap, was this recent stay in hospital with Bruce. David's brother and his wife came and visited a lot cause they were living over there. But there was an occasion where David's mom and dad who are mid-sixties, very active, very healthy, not a thing wrong and are healthier than David and I put together. They had occasion to be just outside of Regional Center for three or four days for a family wedding. Bruce was down and out and sick and, you know, at one point we didn't know if Bruce was going to make it. That's how sick he got. And they didn't even come to visit in the hospital... That really turned me off quite badly.. I can't forget it. Yet I haven't been able to say anything about it. Because, well, my mother-in-law said how badly she felt that she couldn't have done more. But I believe she could have.

I believe they all.. not a card.. well my in-laws called every second day just to see how it was going but sometimes that was more of a drain on me. To have to go through what we've been through all day.

"Misc." emotions (parental)

He's quite pleasant to look.. well you see now I don't know Barbara, like most.. people do stare at him because he's got some fairly gross motor movements about him.

...I have a lot of resentment, I guess, for some of David's family... I think he probably does too. We don't get a lot of support from them.

To be honest we have a bit of resentment when we hear one sister saying to the other, well I'll take your kids this weekend, if you'll take mine next, and all this. I know that Bruce is not easy to look after and people would have struggles with that but there's a lot of things that Bruce likes to do like just go for a drive in the car. I keep thinking that it wouldn't kill them, if they're out for a drive, to come and pick Bruce up and put him in the back seat, put his seat belt on, take him for a drive. He's not going to hurt anything or touch anything or..

And that's one of our other fears... Really that hospital's supposed to take kids until they're sixteen. They will take kids I think up to twenty one, given certain criteria and Bruce meets every single one of them because of all of his special needs and things. But we're going to lose that support within the next few years. That's scary. Um, Dr. Curley has followed Bruce well since Bruce came home to live with us. He's very supportive. He's the chief neurologist over there right now, I think. Although they work in a team over there. So it's really hard to tell who's who. They don't sort of get into these I'm the boss sort of thing. He's been around and worked with Bruce for a long time.

SERVICES

Social Services

I've often wished that I had help to clean the house and for people to come in and help me with that. But that's just another expense and it's certainly one that the department of Social Services isn't willing to pay. But that's another... I have quite a number of gripes with them. I think they abuse, especially parents of disabled adults. It's like slave labor, looking after people with disabilities.

...The whole system just changes when you leave childhood and go into adulthood. The mentality of the social service system is more of a welfare mentality and you're treated differently. You really are. I felt it right away. We were getting children's services through the family support program they have here. It was much more individualized. There was much more trust.

We were getting some help to put in a stair lift. It happened after Bruce became an adult, so we'd make an agreement where... they certainly weren't prepared to pay for the cost of the whole stair lift. They're very expensive. So we split the cost with them. I made it quite clear that they could either send us the money, or we'd pay for it first, or whatever they wanted to do. Anyway some welfare worker, on his own, that I've never even met, who says he's Bruce's worker... his financial worker. (And I've never met this man.) Took it upon himself to call the company, a local company who was supplying us with the chair, and inform them that this person is on welfare and they were to bill so much to the department and it would be paid. Well I was just devastated... I call once a week, I want to speak to him about what he's done. He won't return my calls.... they just start to treat you differently. I just feel that Bruce... or we don't get the same respect now that he's an adult, that we used to get. The same privacy is not afforded us.

Services/"The System"

Well I guess I mean systems like Social Services. I guess I mean people in authority over you who have control and power and make the decisions about what's going to happen.

Oh well, it's a lot like doing lifestyle planning on people but looking at all needs. You contract what they call a broker who helps you to plan and identify your needs. Who then sets out and about looking at the different services around, which is hard here because our services are limited anyway. If you live here there's one vocational service, so how do you shop around? But the ideal is in shopping around and getting what you want and having the money attached to the person and not to the service. This way people are funded to buy their service, verses having services funded who say we're going to run this kind of universal program.

They don't understand... they just don't understand. Well, this is what we have for you in the way of services. Well we don't need any of that, I need all the stuff that you don't have... Cause they've just got stuff for people, say, who can't afford certain things. But that's never really been our issue. At least not lately. When we were first together it was an issue. Now it's not really an issue. We need the stuff that people think, gee that's not the service we give. You get that from your family or you get that from...

And we've been to places like the Society and we're saying look there's a real need for a system change here. This is not just our problem. Families are running into this and you just get the line well, you know if you want to make a change, well we'll have a meeting and we'll all take on a job and I can't take on another job. I can't do it. I have no more time to take on another job.

I think I've said most everything. Some of it in a round about way. I just think the system stinks. It's certainly not responsive.

School (descriptive)

They just set up a regular special education model, you know, special ed class in the regular school, making it very difficult. Plus they're high school teachers who aren't, in my opinion, getting the leadership they need as to how to make that school a welcome place for the kid with disabilities.

David stays with him until the cab comes to take him to school cause they don't let Bruce go on the school bus because of his seizures. They won't let him ride the bus. Plus he doesn't attend his neighborhood school so the transfer in buses... they just can't make it work. They originally put him out of his neighborhood school and then when he made his friends, and they went on to the senior high, we insisted that he go to the senior high they went to, even though it wasn't the one he should have attended. Plus we didn't get a very welcome reception from the senior high he should go to so, we thought at this point in time, his friends are getting licenses and cars and so it's not really the same barrier as it is being removed at a younger age from your neighborhood school.

Education (parental involvement program planning)

Well we tell them what we would like. And it's not just based on what we want. I mean, it's based partly on the fact that we feel we know Bruce better than anybody in terms of what he needs and how best to meet his needs. But we've gone to great lengths, Barbara, to ensure that we're not just airy fairy crazy people. That some of the stuff that we believe are needs of Bruce's are, in fact, justifiable. We've gotten things from places like the J.B. Children's hospital and his speech and language pathologist here. And I remember the speech pathologist, here, initially talking about Bruce's apparent inability to communicate or peoples inability to "read" what was really happening and that we needed to start giving Bruce things like choices... When we relayed that to the school, they said, "Oh my God we can't give him choices! He'll choose not to do anything." They made an assumption that Bruce would just choose to be lazy and do nothing. In fact, they found out the opposite to be true.

In fact, it (being given choices) really motivated him to want to learn to do more things. But even going beyond our own expertise to other people and trying to create some kind of a change in the programs and make his program closer to that of other kids, that's just been one up-hill battle after another. Just constant. Even things like his drooling became an issue. "Well, you can't put him in a regular class because he drools!" It was just one thing after another.

School Struggles

We have had struggles at school for a couple of years, which is really unfortunate, because Bruce is the kind of kid, if he is not happy and something is wrong he is not the kind to lash out or hit anybody or hurt anybody or bash his head or do anything weird like that. He internalizes everything and he just shuts down, basically, so that when things aren't satisfying to him and he is not happy he just shuts his eyes and falls asleep. He doesn't really fall asleep because he walks around the school with his eyes closed. You can't be sleeping and walking around with your eyes closed but that is his behavior. That is how he copes. He just shuts down. It's the one thing he has control over.

Now I spent a lot of time last year being on the receiving end of the phone calls from the school... come and get him, take him home, he shouldn't be here, and all of this stuff. They would always call me first at work. Always call me first... I would get messages or I would be told later by the teacher that she was very disappointed in me in that I wasn't available to come to the phone right away or that I had gone out to a meeting or just horrendous silly kinds of things. Anyway it just got to me. I put up with that for a whole year, practically. We write back and forth in a book about Bruce to the school, just because of his inability to share with us everything we need to know. And I would say I'm not going to be around today, you'll have to find David if you need anything. But still they would call me first. I found that very taxing. And just because of that... and with my new responsibilities this year and under new employment and you just can't get up and go when people call. I just can't.
David and I talked about it and he's going to take that on this year. I'm just not returning the phone calls. They'll be forced to have to deal with David.

And so now that Bruce is more aware of it (drooling and swallowing) we are going to try one more time to see if we can't just teach it (swallowing), rather than having to interfere medically about it. But in terms of his friends and the kids at school, his drooling is not an issue. He drools all over them and they take a rag and they just wipe it up. They just tell him to swallow and don't drool on me and, you know, wipe it off. The issue is for the adults... The adults have the hard time with it. So that was the issue around trying to get him into a regular class room. "Well, he'll drool on the desk." And so the kids said, "So what, we'll wipe it up."

Last year, when he entered the senior high they put him in for a little bit of gym. But what they did, Barbara, when they put him in a gym class, first they made no introduction to the other students about who he was and why he was coming, in ways that the students could welcome him. We talked to them about that. So then, they went back. They backed up and they tried to prepare the students. They changed gym classes and tried again. They thought they did very well. But when Bruce entered the class, he played on the side lines, while everybody else did their thing.

And another thing they refused to do was put him in classes where his friends were. That was the only thing we ever really wanted, was that he'd be in the classes with some of the people out of his Circle of Friends. And they were taking things that we knew that Bruce would enjoy. Computer, typing, music, art. There's a course called, I think language arts at the junior high level. Now I'm not sure what it's called at the senior high level. But where they would do report writing. And the kids came up with this one at a Circle meeting. Let Bruce come to the first half hour of this class because we write in our journals and he could sit with us just like in junior high. One person would sit beside him because he was drop seizuring in junior high... they'd sit beside him and if he'd drop they'd catch him. So they (the kids) had no problems with Bruce. They come up with this plan at senior high, that he could join this English class for a half hour, while they wrote in their journals. And while they were writing they would read to him what they were writing because he loves to be read too... You know, and it's not an instructional time. So it's not taking away from anybody. And Bruce's special ed. teacher didn't feel he was ready for that. And by the time you fight the issue the semester's over and the kids have gone on to something else...

Bruce has always had a teacher assistant due to his epilepsy. He's always got someone paid to be with him at school. So, when we first started integrating at the junior high, it was based on, "Well there's a teacher assistant going to be with him so, you don't even have to take responsibility as a regular teacher..."
But over time, the teacher was comfortable with having the assistant just go sit in the staff room or do something with somebody else. Between the teacher and the kids, if something went wrong they'd just run and get help if they needed help. Nothing ever went wrong and nobody ever had to go running... But at the senior high it's just been one road block after another. Some of it's coming right out of the special education teacher.

Friday they said he fell asleep on them. I thought, here it goes... Like I said to you earlier, that's Bruce's way. That's what he can do. He can just shut down on them. He's real good at it. In fact there were a number of occasions last year where they would call and say look, he's out of it. He's sound asleep. This is not productive. Come and get him. And the minute David would walk in the room, and say "Bruce", he'd get up, start laughing at them and run out the building. And them just looking, you know.

Back in June, an update on Bruce's lifestyle plan was done with some help from the folks at the technical school. Miss

Maxwell (Bruce's special ed teacher) did agree to check out a couple of courses for Bruce. On his typing, she would look into it, but she was not supportive. To me that's just setting it up to fail. When you don't have a teacher coming forward with a very positive approach to a regular teacher, you know. These teachers have been in this school forever and they don't know why "these kids" are here to begin with. They are very much afraid... So anyway, she did make the commitment to check out two or three courses to see if ... Two of Brett's friends, Marie and Paul were at the planning meeting. It was great to have them because Miss Maxwell would say things like, "Well, he couldn't really go to typing class because it's usually always full." Every time we asked by the time she got around to checking the classes were full and there was not room for Bruce. So we said, "Well, this year if you could supply the desk, we would supply a typewriter." And there must be three square feet where you could put Bruce in a desk. Kind of a back up but, you know, we run out of tact after a while. And we just say things. Anyway, she promised to check it out and she felt that if he got too excited that he might scream or something. But Marie and Paul said, "Well, that wouldn't matter, because once you get your instruction and everybody's banging away and typing, nobody would hear Bruce scream. So they're really good to have there. They're a good support. Anyway she lost that little battle and agreed that she would have to go and check it out.

He wasn't there (in school) that much. Um, I would say that from September until December, David and Martha were probably there half a dozen times. No, no, they called us in before school started, we were in the week after school got going, we went back the end of September. Ya, well we were in a lot. We were in again in October. There were concerns that maybe stuff around seizures and Miss Maxwell wasn't sure if she was dealing with his seizures properly. I would say in the four months we were probably there a couple of times a month, on average. And then when he came back (from hospital) he didn't go to school right away. He came back from hospital early May. We got a phone call. As soon as they heard he was back we got a phone call saying, "We trust that you're not sending him right back to school. He's going to need time to recuperate..." I always constantly felt like people were trying to insinuate inadequacies on our part, constantly. So it wasn't just visits to the school. It was all the other stuff that they had us running around doing... Just totally exhausting us. We brought him back and had no intention of sending him back to school after being six or seven weeks in hospital. But they wanted to make sure that we had no intention. And then when he was ready, we had to have a meeting before he went. We had one more meeting after he was in school and there was one more after he came out of school. So that was from mid-May to the twenty second of June. We met a lot.

But it's just so exhausting and what we were doing was getting caught up in their game and having no time. Bruce just had a total.. almost non-year educationally, last year. And there were times when Bruce was "up" and ready for learning.

We send them video tapes. We're just constantly trying to do something. So if it's not a phone call from the school or bringing him to the doctor so that they can hear it from him so that we're not telling them lies or... Because there's always insinuations that we're keeping things from them...

We're trying very hard this year to get off to a good start, to keep things positive. We got a lot of his video taping of his summer program this year. Which was more educational looking than in past years.

So she did some video taping to show to the school. And one of the instructors from the college, in fact, Stewart, the man that I'm filling in for this year. He's Mary Winston's counterpart, he's helping take some of the load off of us. He'll meet with the school, and because like I said, it's like oil and water at this point, he will introduce the video taping of Bruce. Estelle did a wonderful report...

So Stewart, if you ask me, he's supportive... He's another unpaid person. He's volunteering to do this and he's going to go forward with Estelle on this report, with the video tape and see if we can't get off to a positive start about some approaches with Bruce. The taping is wonderful stuff. Bruce is doing all kinds of neat things and he's working really hard. The really interesting thing that I observed when I watched the tapes, is that it's not so much what you do with Bruce it's how you do it... If you have a good relationship.. if he knows you care about him. It's just like everything else, if he knows that you care about him, (even) silly boring things like putting beads in a can. He'll do it even 'til the cows come home for you.

PERSONAL

"Dad"

He would leave. He dropped Bruce back off at the end of the day and would drive out to the end of the driveway and stop the car so that he could have his cry.

David said that he always knew, you know. I think for the first 4 years of Bruce's life he and his dad spent a lot of time just rocking in chairs and just listening to traditional music. So he is into the old bag-pipe and fiddles.

Yes, David is a terrific father for Bruce. I guess he always has been, long before I was in the picture. David takes on.. I wouldn't say that David takes on half of the load of looking after Bruce. I tend to be the one who would sit up nights, if need be, and stuff like that... But just in terms of.. when everything's going smooth then, it's about half. He showers Bruce every morning. He takes care of his personal care in the morning. Um, helps with his dressing, cooks his breakfast, sits down.. I don't eat breakfast. David cooks the porridge or the eggs or whatever and the two of them sit here and have their breakfast together.

(Mother's) self-concept/self-worth

I feel good about myself. I am, I mean, I don't think I'm a bad person. I think I cope reasonably well. Sometimes I get a little overwhelmed, I have to admit that. Um, I have a very busy life.

(Mother's) personal needs

You know there were times when even though you were sort of going all out and Bruce wasn't feeling well, you needed somebody to help meet your own needs too and I sort of felt a real imbalance, like a major imbalance.

I took the summer off and really needed that. Because initially when I took time off, I thought, I'm not sure if I want to work anymore. Like I'd gotten to the point that I didn't know if I could handle it all anymore, because it had all just been too much. I thought to heck with this. We'll just live at a different standard. We'll just, we'll make do. Because I can't, I don't know if I could handle it anymore. But time away gave me some perspective in that. No, I want to work. I know that at least for the next little while, I want to try to continue to work. I want to try to meet some of my own needs too.

Because, I just can't keep it up. I can't keep juggling it all... something is going to fall apart at some point.

I worked in my flower beds and stuff like that. And there were a lot of times... just doing nothing. Sometimes just doing nothing felt really good.

I spent my mornings with Bruce. He had his summer program in the afternoons. I had my afternoons to myself. Go to lunch with a friend and sit and have lunch and sit and look over the water. You know, just the things that.. Where I worked before I couldn't even have lunch.

My new work place operates on a very cooperative basis and it's going to be nice. Ya, I'm looking forward to it. It should be a good year.

And I know that over the coming year there will be more opportunity to do that. I will have time off at Christmas and in March break and all of those kinds of things, so that was probably a real.. That was uplifting for me to be able to look forward to knowing that that's coming. To knowing that um, I don't have to work over lunch break and whose going to look after Bruce?

Care of self

We'll just go sit on the deck and David will read his book and I'll read my book or work with the plants. We also believe it or not, have fun with Bruce... We get down on the floor and we start to play with him. That's fun. I like that.

So we sort of get into taking care of the place and puttering around and fixing it up, if we can. There's pleasure in doing that. There's a lot of fun in doing that.

Inner strength

I guess my conviction. It would have to be that. I just so believe. And just my love for Bruce and... Well I think the same holds true. I think just our ability to support one another, it helps to build on your own inner strength and your partners.

Volunteer work

I'm an adviser to the People First group. I sit on the board of a citizen advocacy group. I'm a member of the local society. So I get involved in a lot of that kind of stuff too. I dropped a bunch of it. I used to sit on the equipment library committee and I'm also a member of the education coalition. So there's a lot of that stuff too. I don't know. But I really get a lot of satisfaction out of these volunteer commitments. I really enjoy it. I love it.

Parental friends

But it's the kind of relationship that when you're together or when you're talking it's like you've never been apart. You can just make a really close connection really quickly. I saw more of her during that time or heard more from her. Whenever I'd make my next trip back she said, you must tell me as soon as you get over and see him and just tell me how he looks. What does he look like? Does he look better than the last time? And on occasion I'd be over there for 2 or 3 days before it would come to me, I'd better phone Alice and let her know. I'd call her and she'd say, "Oh my God, I've been waiting for your call, how.. is everything o.k.?" Just knowing that someone cared... nobody could do anything that the hospital wasn't already doing.

Really there's not a lot of time you know. I guess the thing I'm grateful for is that the people that... um, there's only two or three people that I'm really close with. Um, but they know and they understand and they're not the kind of people that say, Where have you been? How come we haven't heard from you?

I love to have people come. I used to have a real conflict with my mother, for example, "You never come to see me" and I'd say, "Mom, I'd love to see you but you'd better come here. It would be so much easier." And then that got worked out the same way with some friends. It's easier to just... if they'll just stop by, or have chats on the phone. But they might choose a lot of um, spend of my free time too involved in other people's disabilities.

SURVIVAL

Positive support

Now, on my side of the family, I don't have very many here. I really only have my parents who are around... Both of whom are elderly and not real well. They love Bruce to death and they come to visit, a lot. Bruce just loves my mother. She's this really big woman... Whenever he sees her there's always hugs for me and she's always got kisses and stuff like that for him. I think my parents give what they can give him. But my mom's in a wheelchair herself and just really not able to do a whole lot. But you know they constantly call. They were concerned when Bruce was in the hospital.

But you know we've done our best to try to open up as best we can to the people who make it easy and that's certainly not family. But um, people like Mary Winston have been extremely helpful to us. If times got really tough, um, Mary would certainly be there. She'd be somebody to talk to, and somebody who could.. somebody who had compassion but yet was removed enough to be able to say, "Now wait a minute here, we should look at what we can do that's going to get you what you want." Because you don't go and cry on Mary Winston's shoulder. You come away with things that you can do, positive things to help change and got things more the way you really want them to be. And she's been a real big support.

She would actually stop and ask, "How are you doing? Are you getting enough rest? Do you have people to come to spell you off when you're over there? She would ask questions, that if the answer was no... I'm not doing o.k. and I don't have people to come to spell me off... it's not that she could do anything about it. It's just that she thought that. She knew that, that mattered.

There's Bruce's family support worker, or whatever Betty is. She does her best in her limited authority within the department to try to get things for Bruce. She will go to bat. She will take things up the line and say these people need this. So I have to say that Betty has been helpful. The difficulty is that once the wheels kick in, in terms of processing how things happen, Bruce just gets lost. I have a big problem, with how things have to be processed in that placed.

She would come over to the hospital and sit with me and visit with Bruce. Or just visit with Bruce and say to me "Go, I'll stay with Bruce for an hour or so. Stuff like that. She's been a major source of support, actually, over the summer... I don't know what happens next summer. She's teaching away. I know that she's not going to want to come back to this work. But for the last two summers we've been free of worry. and knowing that Bruce is having fun and he's with someone who cares about him and he's learning.

Before he turned eighteen, Betty was the only person we had to deal with. She took care of everything. And you could handle things financially the way you chose. I mean if you wanted to be paid once a year and take your money, you could take it. It doesn't work that way anymore. I just find that it's more dehumanizing now than it used to be. But certainly she is supportive in saying yes, if you say you need this we believe that you need this. And that, I guess, comes from her experience of working with us to know that we're not out to rip off the system or to take things that we don't really require. So she's somewhat helpful. Um, other than that it's sort of just friends or people who care about us or care about Bruce. We don't have a lot of people paid to be in our lives that we find supportive...

I just don't believe that a place like the general hospital could ever operate like a children's hospital, where they work in teams and where parents are so vital and important in the process of getting well and getting kids better again. The children's hospital just make you feel if you weren't there, things just would not go, as well... They really value family.

The principal was a really welcoming person and wanted to try this out. We sent him to the next province to see some of the stuff over there, where they were integrating kids successfully. He went for three days. He saw some wonderful stuff at the senior high level and came home all excited. But he doesn't have a lot of support around him.

Ya, well we've had a lot of it confirmed by people at the J.B. Children's Hospital that chances are if we don't know it, they don't know it either. Now, of course, obviously they've got some medical training that we certainly don't have. But just in terms of Bruce as a person and what's really happening there, I don't think that they would... I would seriously question if Bruce would be here today if it were not for our ability to act on his behalf, to know what's going on with him... For others it (parental involvement) is just lip service. It's on paper. They believe it, parents are important. If you never show up for a parent interview you're labeled too. But if you do and you try to get involved uh, there's sort of a line. Like get involved but only this far.

Spousal support

Boy, I think if it wasn't for just having somebody like David. You know where the two of us... we experience the same kinds of feelings. We have the same kinds of hopes and anxieties, or we seem to. I think we really help one another.

I was feeling a lot of pressure from work and all of that stuff. And when times like that happen, I get overwhelmed. It gets a lot harder to cope. Not impossible, but a lot harder. And if you don't have a partner that you can lean on (and there's a lot of strength there) I don't know what would happen. You know, you might sort of want, then, to throw in the towel.

Siblings

Doug now, comes around a little more. This is nice to start to see happening. He'll come to dinner and uh, he's just uh found himself a new partner who has a six year old, which is a whole new life for Doug because he's only 21 or 22 years old. He'll be 22 in a month or so. But they'll come over and they'll have dinner and he'll talk to Bruce. Last Christmas he bought Bruce his first Christmas present.

Doug has started to see Bruce very differently. We were over when they just moved into their new place. He invited us over to see their place, so the three of us went over and Doug said, "Bruce is really doing great isn't he?" He's starting to notice.

Relief from stress

So I would say he's really been quite well and we have been able to, sort of, sleep again ourselves at night and stuff like that. Yes, sleep deprivation for everybody is just terrible. I don't even remember sleeping for months. I don't even remember. Not that you can do anything you know, but you would sit up, just sit beside him in bed and just watch him, because I felt I had to.

...those kids just took an awful lot of pressure off us and gave us a bit of our own life back. He would go to their house for dinner and to me that is a major undertaking. Bruce has a lot of needs. He is not toilet trained (for example).

And another thing is that I don't think about Bruce. I don't think abuot school for Bruce. I get in there (work/job) and I get so busy that it's not possible, plus I guess part of it's knowing Bruce is probably o.k. right now. I'm quite concerned about his program and how we're going to find time to make sure that he's got a quality program now that we've got everybody convinced that he's well again. But, so there's a lot of that worry gone too, which allows you to be freer, to enjoy what you're doing.

Of course we're tired. Things are better now though, since Bruce is well, and sleeping at night...

Strategies

I get mad a lot. And sound off. And in fact ... it has worked. I mean, if it were not for all of our pushing and sounding off, Bruce would still be sitting back in the junior high school. The classic (traditional) high school would never have opened.

Ya. But one of the things that David and I never do is go to any meeting about Bruce without one another. We do not do it. Because you can always... If one's going to lose it, the other one can maintain composure and think about what to say next. And I find that to be very helpful, to be together.

I guess there are some sacrifices although I'm not sure that I would call them sacrifices. We don't have a major social life with people, because we have to make some choices. And you have to take care of yourself. We have to be well. Cause we've got a lot riding on our being well.

Life waits until the weekend. A few days until we get rested up. And it still gets overwhelming. As I said to you last night, I would dearly love to have a neat and tidy house but I can't. Unless I'm prepared to allow someone to invade what I consider my privacy and come into my home and clean up after me. So far I'm not prepared for that. I'm not ready to say that I need that much help yet. I'm sure it's going to come. That day, I know, will come. Because we have no vision of Bruce leaving us or living anywhere else. This is his home as much as it is our home. And God forbid we should turn him over to a group home. You know that's just not in the cards right now. And so what's going to have to happen is we're going to have to open up and accept some more help at some point. We know that. It's just not yet.

...Just little cues you give to one another, tells the other person that "I need you, now, to do this." And you just do it. The other thing, too, that's been helpful is that we've learned that our house can never be neat and tidy. It can be clean but it can never be neat and tidy and everything can not be put away. Some things are just more important than other things.

But we always make time for both to be there (appointment, school meetings etc.) together. And if we can't then we have to say no we have to cancel because one of us can't make it. And we just wait until we can both be there.

But it's the way you figure things out. You have to go and check things out and you have to be prepared for not always getting the answers. But we find out what the answers aren't. And maybe through all of that you get some of the answers to what's medically happening with Bruce and what we might expect. But it's still...David and I are just out there and we're fighting the system. Things are starting to happen around the school and getting some people to rally and help support, but you wonder how much you get out of just volunteers coming forward and saying I'll go do that for you. How long will they go do that for you? Where's the safe guard there? That whenever you need it, it's going to be there?

"Interface" and community

In fact we always shop at the K-Mart and everybody knows him now at the K-Mart and will all say "hi". Um, It's interesting. One of the things we've discovered... He recently got a wheel chair, because he was so sick. We wanted to keep him moving in getting him out and stuff. Walking him was impossible. And at times still can be. He's still having difficulty with um, long, long walks. He's still got some problems. He was so run down that if we were doing a lot of running around we would take him in the wheel chair. And one of the things I've noticed is, he does not get stared at as much, in the wheel chair... Somehow the wheel chair makes it o.k.

Changes that can give hope

What's so important to me is having the ability to make decisions and to have power about what happens...

I think what really struck me, was the fact that.. Was the summer tutor's interaction with Bruce. Then all of a sudden I really realized that not only does she understand and internalize where he's at and what he needs. But she does it so well. Maybe it is part of her being able to put herself in Bruce's shoes. There was also a lot of just warmth. You could sense it, you could just see it happening. She took great delight in very small accomplishments. What most people would call very small accomplishments. Estelle would just hit the roof, jumping for joy.

And you could very quickly see that she cared about him so much and that his learning was so important to her. It then became important to him. Because he saw how much it meant to her and she meant something to him. He's very sociable... wants to please... loves to do well. So they sort of fed off each other.

Just her approach, lots of touching and "That's great Bruce" and "Do it again". She laughs with him when he does funny things. You can just see it all coming out and he is picking up on it.

Education

It's a parent based-program. Parents must enter their children into the program. Parents must decide on what the program will be... if they choose to involve teachers, school systems, whoever. In terms of what's most important for the child... that's their (parents) business. If they choose not to (involve teachers, school systems, whatever), that's o.k. too. The only thing that this program insists on is that parents are involved in setting up programs and determining priorities for kids. Every child who enters the program gets one-on-one tutoring. There's no grouping of kids, there's none of that... The parents volunteer to raise the money to come up with the program every year.

So the parents of kids with disabilities raised the money and we hired university students. We give them three weeks of training. We train them in different disabilities. We assign them a case load of kids and some people might have two kids on their case load. No child can have more than four hours a day of this program. Any more than that and you can't call it a maintenance program, when school's only six hours. No child can have more than four hours a day. We always trust that parents know what's best. Some parents choose an hour, three times a week. Some parents say, my child needs it every day or they're going to regress. We trust in what the parents say. We always try to do for them what they believe is best for their child. So every tutor is going to have a different case load. A case load will fill their day. They might have two kids a day, they might have three or four. And the programs are designed between the coordinator, the tutor, the family and if they choose, the school.

I think they're comfortable with the old traditional way of doing things. But what we discovered was that Bruce's priorities didn't change a whole lot. Even some of his activities didn't change a whole lot in what he actually did. But if you took him somewhere else to do it, it made a difference. If he had a new place to do it in.

She read Bruce's communications. She seemed to instinctively know it. Although we talked to her about the fact that you really have to watch Bruce to know him.

How do you get him from where he is to where he needs to go without making him look childish? That's our challenge and we'll help you and you help us and together we'll figure out ways. This is where we come up with more and more computer, cause that was a really good kind of thing.

CHILD

Child's Characteristics

Well the characteristics of Marianne, I guess are the typical ones of the Downs child... very lovable... fairly good-natured, I'd have to say. I would describe her as fairly good-natured. And there's always something in each passing day that kind of gives you a lift. By something that she does or something like that. She can be stubborn. Lord, Lord, Lord. She can be stubborn. Let's see now. Well this stubbornness, it would have to be her most negative, most negative thing. I would have to say that was the only thing I would consider... That's the most stressful thing to deal with is her stubbornness.

Communication

Speech is very, very poor. Uh, her biggest delay is in the area of communication. She has to communicate by the use of sign language. And she does have problems. Her verbalizations wouldn't be at all clear to a non-familiar listener.

Child's Play/pleasure

She loves to dry the dishes and things like that. Make the beds and fold the clothes and she's the neatest child I have. She always picks up what she lays out, always puts it away. She's the neatest. She hangs up her coat and things like that.
She likes exercise. She doesn't very often sit.

Knowing/learning

Because I look at Marianne and the little that she could communicate to you that you'd be able to understand, but yet I often wonder how extremely smart she is. She's at a double, double disadvantage in that. If she had the speech, she'd be really spinning their heads down there at school. She'd be just spinning them... Because even though her communication is poor, she lets them know that she knows what they are teaching in the classroom and... "Don't count me out!"

She imitates those two boys an awful lot... An awful lot. In their actions and in their movements. She models their actions. For example, if they score a goal in hockey, or their wind-up when pitching a ball, or doing their homework, and things like that.

Child's Friends

I would say her first year at school was her best year as far as friendships... Now I think maybe it might have been that we hit a better set of parents. Not a better set, I shouldn't put in that way, but a more understanding group of parents... In that Grade one room where she was first integrated, because she had a lot of invitations to birthday parties and things like that in her first year. Her second year in Grade one you could see a decline in that type of thing. And this year, or course, it's too early to tell.

There's a group of children she plays with at recess and lunch time. She's not a loner. She's not just in a corner somewhere playing. She's in a group when she's playing. Terrance quite often goes over at recess or something and shoots a few baskets with her or something like that.

STRESS/ANXIETY

Parental Stress/anxiety

I'm no hero. There were plenty of days I said, "That's it, I am not doing any more. I don't care where she goes or what she gets into. I am not fighting anymore. And I'll keep her home"... Mind you it only lasted a short while. Then it was time to start again. And you do.

In a matter of one phone call, I got the other two registered in school. To register Marianne was an eight month process of meetings and phone calls. I can call and get the boys into hockey or anything. I can't do one bloody thing over that phone for Marianne. It's a meeting, then there will be another meeting and they take it to somebody else, for another meeting.

If given percentage-wise I guess maybe I'd only give myself seventy-five percent patience response. Like being patience to deal with that, O.K.? I'd only give myself seventy-five percent. The other twenty-five, I think I react be being frustrated, which makes her more frustrated and more stubborn and the whole family unit then is frustrated. It's difficult... And I don't know what it is, why some days I think better than others. I don't know. If I used the same mode I guess every day or whatever. But some days I just... I let her stubbornness get me frustrated.

Even as she gets older, we wonder will she ever be able to be left alone for a short time?... But with her communication problem, I don't think I would be comfortable enough to ever do that... If she couldn't get a message across on the phone or something like that. I can't see babysitting ever ending.

I remember a six page report from a speech therapist, done immediately prior to Marianne's entering school, that when I received it in the mail, I actually cried. Of six typewritten pages there was not a positive thing in it! It was a total list of what Marianne can't do, not one mention of what she can do. A report like this is extremely disheartening. I already know what she can't do. There had to be something positive to build on. It gave me a sense of hopelessness and total frustration. Why would I want to return to see this professional who had nothing positive to say and no recommendations of how we can help in Marianne's problem areas?

A lot of the professionals you deal with... you come home with the feeling of being disheartened. Of the majority of them I have dealt with I can honestly say that. That it's disheartening.

There are reasons to doubt. You know, we're worried about all our children walking home from school and everything like that. But your other children can handle the situations that might come up on that road home, whereas I don't know if Marianne could handle some situation that she would be confronted with. But then again, I'm not always going to be there... She is going to have to handle some of this on her own and her brothers aren't always going to be there... There has to come a time definitely.

School wasn't even focusing in my mind at that time (at Marianne's birth). There would never be school (I thought). There would never be birthday parties. They'll never... There's a whole lot of "nevers" that was going through my mind. You know Brownies, I thought she'll never go to Brownies. She'd never, impossible.

If anybody is sick in the family, I'm stressed over that. Financial demands make my life stressful. Dealing with professionals makes my life very stressful.

Disability and Stress

They weren't particularly sure at that time that she was actually a "Downs child" and it took two days of investigation to confirm that. It was at that time that the doctor approached us with the news that she was definitely Down syndrome. It was a very difficult time. It was a stressful time for everybody in the family to realize that the child was going to be disabled. As far as family members having to realize what was taking place, her other two siblings were only young at that time. Her oldest sibling was only three and a half and the other fellow was only eleven months old. So, as far as any kinds of interpretation in their mind's eye, they didn't understand any of this, anyway. So it was just my husband and I that had to actually deal with it from the time of the birth diagnosis.

Stress (Financial)

I didn't ever have to get too much of the special equipment. Other than physiotherapy... I did get some walkers and I had to get some wooden canes and I can remember, having a carpet roll made up at one of the carpet places when she was very young... to get her knees intp the crawling position and all those wonderful things. None of which were terribly expensive.

They (sitters) are not in plentiful supply, There are some girls that I can get that are very reliable. But it's costing double because you pay a good amount of money for somebody that you know, will do it, and is reliable.

Demands on Parents

They (father and brothers) never really did have a keen interest in acquiring the sign. Not to the point that I did. But I think what happens, too, is they depend on me to know what she's saying, you know. I still have to interpret, here. Although they get along fairly well, I really do think they could do better.

She was so sick and ah, I just... I didn't have anything... I didn't have anything else in my life other than her physio in the morning that I did and... An outing for me was to the clinic or to the hospital for an x-ray.

And you have to consider, too, that while I was doing all this through the space of my day, with her, I still had two other young lads. I had one fellah, five. He was off to kindergarten and into school and things like that. But I had another little fellah here.

You know, there were plenty of mornings that I'd be doing the physio or something and the neighbor would come in and leave because she couldn't stand it... seeing me do this... trying to get those legs straightened up. I'd have Marianne plastered up against a wall, and she was just screaming her bloody head off... And all that the neighbors could think was, this was too cruel. They can't witness that. So they were free to go out the door... I didn't want to have her crying either... But I wasn't free to go... I had to put up with that. I couldn't go out the front door and shut the door and be gone.

We take her skating and swimming and things like that. We don't allow her to get into a rut. I do go two days a week skating and one night swimming. So you know, it's another constant battle. If you're going to do that for them, it's you that,s going to have to do it, so you might as well get busy and go and do it. It all falls on the parents' shoulders... I'm busy keeping her busy... It's not that I can just send her down to the rink by herself. They have skates now. We come home at six o'clock.

And it's... others don't realize it's an extremely different situation. If she's going to benefit from it, it's because of our efforts to make sure she gets there and does it.

I haven't explored those groups (Brownies or Guides) to be truthful with you. I had her in a catechism program a couple of years ago at the church... I didn't find my reception overwhelming... And I was... usually I'm not one that will back off because my reception wasn't good. In fact, that gets me going all the more. I'll usually admit that quite freely, two years ago I was struggling here with the school, you see. Trying to keep that on the up and up. And I didn't know if I really wanted to tackle the church too at that time...

There's a limit to what you can do and what your head can hold. So I let that go. It wasn't what you'd expect from a church. So there's a real kick in the teeth, as far as I'm concerned... practice what you preach type of thing.

Respite care would be one of those (special things) that we've had to do. Baby-sitting for us, well, is it ever going to end?

My neighbors can go away for a weekend and they can send the child to their sisters or the grandparents or whatever, here I'm confined to the respite care worker.

There was a big problem we faced, whether we wanted to keep her in grade one for the additional year or move her on with those kids. That was a toughie. That was a toughie as to what to do. We hated to lose that group of friends because they're now in grade three. They still play with her and everything but there's not that same kind of closeness.

But we decided for the additional year in grade one because we had such a terrific teacher. It's the way we went. We were pulled both ways, believe me.

There was a couple of us that started it and approached the hospital to see if they would give us the pool... It's small. It's a relatively small pool but the water temperature is terrific.. We're talking at 98 degrees. It's wonderful. We'll never want to go to another pool. That's the problem.

...Generally, yes, I am satisfied with my life. There are times that I wish I had more freedom of movement in the sense that I always feel that I have to be available to whomever may have Marianne, whether it's school or whatever. I don't feel that I can just cut loose and not be too far away without... a phone call away or something like that. It was definitely harder when she was younger and the boys were young, as well. I didn't have the freedom to go as much as my friends could go... out in the evening or things like that. So definitely you're more confined... more so than the mother of any family unit. I would say a mother of a handicapped child is more confined and confined for a longer period of time.

She would walk home anytime from school. Now I think maybe that's me more so than her that's doing that (driving Marianne to and from school). I have to put a lot of the blame on myself. I'm not confident enough that she has the kind of skills to walk up that road by herself... I worry about cars and just different times that I walked with her. If she has a rock in her shoe, she sits down in the middle of the road to take the rock out of her shoe.

Yes, I like the swimming and I like... you have that contact with people with the same everyday day to day situation that you are in. I like that part of it; but as far as skating I'm just there because I have to take her and I have to wait for her... I usually sit and watch the kids skate for a while... I don't get too excited on skating day.

The frustration of... it may not be any different in any other province, I don't know. We always have this two-tiered system in a sense that we still have our Forest Home institution. Handicapped children are institutionalized. And you'll have your other group going more for integration. Instead of that being those two groups trying to work out to a common goal that's beneficial to specific needs. Your needs are different than my needs. So no one wants to work together for the best interests of the individual children, whatever those might be.

I am pro integration. But I don't like the ideas shoved down somebody else's throat. I'd like to see something worked at and worked at reasonably without it being a confrontation.

This was Health and Social Services. That's what they had provided in the first years after Marianne was born. It was from this request of mine, to put trained worker in my home versus putting Marianne in Forest Home, that community respite care started. Put them in the community. And if they still wanted that connection, they'd still have that connection with Forest Home that ultimately... perhaps they were responsible for care. But Marianne wasn't over there. And it's not that I thought she was any better than the other kids or whatever that was over there. And I certainly never questioned the capability of the staff. It was something that wasn't suitable to us.

Lack of Support

The doctor that was attending me at the time, the obstetrician, had no idea in the wide world on how to cope with the situation. So he ran from it, to the point that I was five days in hospital and I didn't see him over the space of five days. He never came back. That was the end of him. He was gone.

It was after the hospital environment that we did hear from some other people... that the burden is awesome. It's a responsibility that never goes away. And perhaps maybe could consider sending her somewhere else.

They were shocked that this happened and offered support by saying, "Oh well, you can handle this." "Things won't be that bad." This was both sets of grandparents and that's on-going. That's an on-going thing right to this day.

I don't think it's rejection. I think it's more of a fear of what to do or how to act or... What would I do in a situation if she happened to take a stubborn streak or something like that? I think it's ah... No I can't say they reject her. Both sets of grandparents, I think, are very fond of her, but at a distance. As long as we are there you know, to be the main caregivers and look after her. But don't expect us to jump in and try to alleviate some of the stress. No we never did have that kind of hands on support. And that holds true to all family members. I can honestly say that there's no support in that family unit.

I don't have a lot of people pounding down my door saying "You want me to take her for an hour?" or "I'll take her some Saturday evening or something." I don't have any of that. I don't have that kind of support. The only hands on support that we've ever had is what we bought and paid for... that is domestic care worker or baby-sitter or anything like that.

Nobody would come near her when she was an infant because... When I look back on it now and thought (at that time) that it was valid. They were very scared to look after her because of all her health problems. Because you could lay her down at eight o'clock and then at ten after eight she could be in real distress breathing. And indeed, that was a valid point. But I wonder if they didn't play on that too? Thinking that, all right that's a legitimate excuse and you know they're going to say they don't want to look after her because they're scared that something was going to happen to her.

We're always present, ya. She'll go in to her grandparents or something but Sam is with her or something like that. Age is a problem there, too. I mean, they're not young by any means. But I think even if I knocked twenty years off their lives, I still think it comes down to the basic thing, that they wouldn't know how to react to her in a certain situation. I think that's why they don't...

I could sit here and talk to a friend of mine about the problems I might be having with the T.A. or something at school... Well they're not in that situation. They respectively listen to you but they're not hearing what you're saying. And it comes to the point that if that's all you're going to talk about to your friends they get to the point where they don't want to listen to you anymore anyway... Because they're not facing that situation. It's not a lack of interest, it's that they're not involved in that situation. So it means nothing to them in that sense.

Miscellaneous Parental Emotions

I was at a complete loss. We knew nothing of associations for this type of thing. We knew nothing, absolutely nothing.

Sam's concern was not so much his reaction but everybody else's reaction. What everybody else would say and think... That kind of bothered him. But he's extremely good with Marianne. he hasn't got in too much to the signing or to try to understand, you know. It's the communication thing that's the big, big problem.

I really don't... I don't have too many regrets in what I had to do over the years. Sometimes I had to compromise in one area to get more in another area. When you look back there were no other options open to you... I look at perhaps times that were taken away from the boys because I was tied up with her being sick or things like that. But there was no other way that it could be done... Because the need was great that was there at the time.

I don't think that anxiety about time away from the boys ever goes away. You certainly reflect back on that. And even the fact that it still happens to the present day.

SERVICES

Services (General)

I think definitely the professionals that are... sometimes maybe they are thinking that the parents are looking for somebody to put the blame on, or something. Maybe they think that's why we are hard on the professionals; but I don't think that's where the majority of us are coming from. Really what we're trying to get across to them more, is just try and see the child as a whole. Just not this child that this mother or father has to deal with. There are others involved. There's only a certain amount of time that you can do it. And most parents, 99.9% are doing the best job they can anyway, or the child would never have even shown up for the appointment... They're doing the very best they can. And I don't think there are too many people that are slack in the sense that if you want your child to accomplish to the very best he/she can. You're going to darn well work and put some effort into it. You're not going to let the child sit in front of the T.V. and all this. And I think the professionals do have to realize that. They have to realize that you have to work with the parents. Don't work against them or nothing, nothing will work out... nothing at all, actually.

Social Services

Not very many people or agencies provide any kind of support. Well, the family support program through the Department of Health and Social Services does. And that... well it's more of a financial thing than any kind of tangible support. By that I mean, they would pay for respite care-workers, for example. That doesn't do us much good, when we haven't got a respite care-worker. They don't have any staff made available to you that can come in and help you out... which has always been the big bone of contention I had with them. Like, just don't send me a few dollars trying to keep me happy. It's not what I'm looking for. I want somebody to come in here for a couple of hours and give me a break... or know that we can go away for a weekend with another couple. That's the support that I'm looking for in a family support program from your department. I'm not looking for cheques. I'm not saying that we don't need the financial support either. We couldn't pay for respite care-workers all the time either... to go away for a weekend. The financial end of it is good but it's no good sending me money if I don't have the person.

School (Descriptive)

She had early intervention. Three mornings a week, we first started with. They increased it to the five mornings. Then just before her first school year, we put her in until three o'clock in the afternoon.

They really don't exert and pressure (to move her out of the school) at this point in time. It has been said to me, though, if... if with maturity, if she's not going to fit into grade three class room, we have the option of moving her up to grade four, or whatever. But I think they realize now, after two years of me being down there, that I'll give them the rule on that. I'll decide on that, ...what I want to do. Definitely I would say they wish that they didn't have her. In a community this size, it just amazes me that she's the first child with a mental disability to be enrolled in that neighborhood school... We're not talking about a new school by any means.

Ya, it's lonely though, if you're the only one in a big school like that. We have an enrolment of 550 down here. It's lonely.
If you had another family that had a child that is trying to be integrated into the system.. it would be better.

They (day care/early intervention) changed the system to accommodate her. Whereas I don't see that in the schools. She has to fit into their specific system, somehow.

And I mean these are the educators with all the education and the brains. Why are they expecting a disabled child to fit into their system? What can they do to make it easier for the child to fit in? You're the one without the disability. Don't put the onus on the child to fit in.

I put her right down here in the neighborhood school, couple of blocks down the road... I didn't have a lot of support, of course. I still don't.

Struggles

I think they have the philosophy here that... Well I know for a fact that disabled children are probably the lowest priority on a list here. And if it's a child just with a speech impediment or something, well they can work on that and see some success. But if you take a child like Marianne where you're basically trying to teach her oral langauge... that's a big job. That's a big job, and they don't have the time or the resources or I think what it boils down to, is there is no interest.

But I can remember my original request for respite care for Marianne. We were told if you want to go away for a week-end or a week or whatever, Forest Home was our only option. That was it. That was all. "Well, that's not for us. That's not what we'll be doing." So if I want the week-end off you're telling me I have to put her over in the institution and tell me to drive away and tell me to have a good weekend. Now you've got to come up with something better than that... I don't want it, I don't want it. Take your worker who has qualifications and bring her on over here. She stays here with school available to Marianne. There's a car available to her. Come here and look after Marianne in the community. And then let me drive away and you can say to me, have a good weekend.

But on the other hand, there were families who wanted respite care provided for their children in Forest Home. I could not with clear conscience, dictate to them that they should have the worker come to their homes - perhaps they wanted to be home themselves for a week-end, without their child. So this was a problem and continues to be so. How do you satisfy both sets of parents? It is not my wish to have institutional care. But how can I tell others what they want? So Health and Welfare Services continues to operate two systems. A lot more work has to be done in this area. Financially alone, the taxpayers cannot afford to pay for "disadvantaged" citizens to live in both worlds!

If I were a foster parent, I wouldn't have to worry about going out working trying to make some money. They'd provide me with everything. I'd get so much respite care and I'd get money for looking after the child and everything. But if we ask them for anything for our own natural child that we try to keep home, it's a fight.

It hasn't been a stressful situation with my pediatrician. But any of the other disciplines I have had a lot of stress... It's the attitude they exhibit. And mind you, you can't put everybody in one lump sum in that. But there's some in the same discipline but have a different approach... that makes it easier for you. But generally speaking I would have to say it is the attitude. And absolutely no comprehension or willingness to acquire knowledge of what it is to have the child for twenty four hours a day, and try and keep a normal family circle going. They can come up with umpteen suggestions that are not practical to implement at all...

I get really stressed-out with some professionals who are hell-bent that the child should acquire a certain skill at a certain age, and if not accomplished, would give the impression that the parents were not teaching it or even working on it. They did not consider if it was the approach being used by themselves or, if indeed, the child needed the skill at this time. Does it make sense to the child?

I had one professional come here, well not here but out in Dover and wanted me at that time (because she looked it up in a book that the child should be able to learn how to open the door handles for getting in and out of your house. Cause age-wise that book said that). Now, the professional, I mean just had to look at Marianne. Marianne was not even on her feet at that time, although she was two and a half. And she used to jump around the floor on her bum was how she'd get along. So I asked the simple question, "Well how am I going to get her up to the door knob? She can't take the weight on her legs yet. That is what we're working at now... to get the weight on the legs... Oh she didn't like it (my questioning her). She didn't like it one bit and indicated that "Mother was unco-operative."

Don't provide parents with a list of do's and don'ts. Ask them "Do you think that's possible that you can do that certain task and without putting added stress on yourself? Would you have time to implement that? And let me know how you're getting along with it, you know. If it's useless, call me up and tell me it's useless. If it's something that's going to work for you, great. Let's develop on it." That type of thing. But they never did seem to have that kind of approach. I didn't see it, anyway, with the people that I had dealt with.

PERSONAL

Dad

Oh yes. He's very good with Marianne. He's always been very supportive of her and things like that. Perhaps it has taken him a little longer to adjust to the fact of a child with a disability. But I think that happens everywhere... I had those five additional days in hospital, too, where I was exposed to her and was the care-giver to her. So I always had five days plus on him.

I'm the walk-the-floor type... but he's always supportive in the endeavors that I came up with as far as skating or anything like that. And if there is any problem or whatever, he will always go and intercede... to see that she gets in. it was the same when we registered her for school. Sometimes it just takes a couple of words from the man. (Which I don't agree with). But I remember trying to get her into school and they had listened to me for months. I can remember him sitting at one meeting and he said to the principal, he said "We both know that you have had and will have children in the school that are going to cause you a lot more trouble than Marianne ever will. So get on with it." And that seemed to be the be all and end all of it.

Whether it was just my exhaustion of having talked with them and wasn't getting to home-base, or what...

He can step in quite easily when he takes her for a little while. "All right, Marianne we're going for a little drive" or "Let's go down to my office and play with the computer." And it always seems to be at the very best time where I say "Oh my Lord". You know she and I have to be separated for a few minutes here. Somewhere, sometime, you know. So it always works out well there, too. And the boys seem to pick that up, as well.

Mother's self concept

I'd like to think that I'm a competent person. I think so, you know. I certainly have the confidence that I did the best I could in any particular situation.

Personal Needs

It was that second year that she was in daycare that I went back to work part-time. I worked the mornings. Well I worked as a lab technician at the capital city clinic but we just got laid off there the other day... The clinic closed. So I did that in the mornings, which was great for me too. I had to get back out in contact with the adult world. I just had too. I just had to make that contact again, because it was too much at home. It was hard enough when you had young ones at home. Everybody realizes that, but when you have all this extra stuff that you have to do for one child.

I had no choice, But, no, I know I could never think that the burden was too much, even when she was so desperately sick. Those were hard times. Oh they were rough... nights and nights and nights of lost sleep. And you'd come home and you'd wonder what could I get for supper? The other ones are crying in your ear looking for something to eat. It was rough going, there's no doubt about it. But no, I'd never, ever tell anybody the burden's too great. You know, it took this two and a half years of physio, but when she took that first step on her own... It makes a difference, makes a big difference, ya.

Well, I don't know if I want to explore more education for myself. But there are times that I wish that perhaps I was a person that could be employed full time outside the home. I really feel, even up to this point, that I'm not marketable to be full time, because there's no employer that would give me the amount of time off required to attend to

Marianne's appointments, that can only be done on a nine to five basis.

I am going to miss my few hours of work each day, definitely. I hope to find something again but... because it was good therapy for me, too.

This is what I mean when you have to work outside the home. It's that space of time that you can forget about... Well I got speech therapy on Thursday and... You can forget about that when you are at work. You have three or four hours of somebody else demanding something else of you. So that's gone out of your mind. Whereas when you're at home your calendar is just basically appointments and things like that.

I know when she was born and they came to tell us, if I had had somebody that could have said to me, (whether it be a nurse or whatever), "Things won't be that bad. I went to school all my life with somebody with Down Syndrome." That would be a big "pick me up."

You know it's just that extra... I mean it's an awful feeling when you're preoccupied with this child with this disability you think of nothing else. And no matter who you ask, they know very little about or what they do know is very gloomy. You don't want to hear it, anyway. I don't know how many books I took home here and shut the cover after the first page.

I could use a little more of action. Actual hands on type of things and...

Care of self

I love to walk and I love listening to music. What else do I do? I read. If somebody gave me five days off and gave me a number of books I'd be the happiest woman in the world. I wouldn't have to do anything else but sit and read, I'd love it. I like to go out quite frequently. I belong to a craft group. I go with friends of mine. We never accomplish anything in the craft line but we have a good time. No I don't restrict myself, I go out.

And he and I always go at least once a year when he has a meeting away to another province. I usually go on that for four or five days, and any other meetings that he might have out of province that I can possibly ask for a respite care-worker, I go... I don't mind it as much now as I did when she was really young. Well, I guess I usually get a fair kick at the can.

...because we could be there swimming with other parents of disabled kids for the hour and all we did was growl over one particular issue that we may all have faced, whether it's a school problem or something like that. Then another week it may be entirely different. Maybe something really good happened. Something was turning out right. So we talk about that. It's just the similar... because we're in a similar circumstance and those are the people that best understand... Somebody else that knows exactly... yes I went down that road. "I was where you are, two years ago," kind of thing...

You always have that kind of safety net where you can say, look your fella's in grade four. What did you do in this particular time? Did you have that problem with him in school? or something like that.

I try to go out for a walk every day. I usually go with my neighbor. This is my time... a half hour to forty-five minutes. We have a real good time.

Inner Strength

Well I guess when I look back, it (inner strength) must be pretty good to go through... I mean sickness and the... And I'd have to say it's pretty darn good because there hasn't been a whole lot of support anywhere else other than in our immediate family so...

Oh no, I don't think up to ten. I don't think I'm a ten, but now it (inner strength) would be an eight.

No I don't get overwhelmed. Thank heavens for that. No. I don't think I overwhelm too easily.
I do have a sense of humor. Cause there are days that you might as well laugh than cry... I do have a sense of humor. I can see that.

I quite readily say when I've had enough, I've had enough.

Volunteering

A lot of things that I find myself volunteering in are all centered around mentally handicapped, except for catechism, I do that for the church.

That has been a kind of blessing for me. At least it's something that I volunteered for; I get some enjoyment out of it. It's not a big hassle to me...

I'm involved with the developmental equipment library for the mentally handicapped for the past six years. I like that. I enjoy that because it's something that you can see that's providing a direct benefit, cause they can come in and borrow these items and use them for their kids. I like something that's actually getting to the child.

Parent's Friends

I have a good many friends all right. They're supportive in... well I can't say... not so much hands on type of things. Like I was saying yesterday, I don't have a great abundance of people saying "Well maybe Marianne can come stay with me for a Sunday afternoon" or something like that you know... If indeed, though, I had to take her somewhere and something cropped up or I had to go home on a family emergency, I know there's people I can call. Friends that would help me out, you know.

SURVIVAL

Positive Support

The pediatrician I found was excellent at that time. The pediatrician, who was supposed to just be looking after the baby, had to take me on as well. From him I got a fair amount of support. Fortunately he's the pediatrician that was in practice for thirty some odd years and has dealt with this situation before. He knew a lot of children with Down Syndrome so that he could give me a somewhat positive attitude about it. Had it not been for the one particular pediatrician, I don't know where we would have turned or to whom we would have turned. The pediatrician's words to us were, when I asked him where do we go from here? I remember specifically asking him that. He said,

"You take the child home and you treat her as normally as possible."

The club is competitive and they try to teach everyone to skate well; yet where Marianne has a problem in a certain area, they try other options that will give her success, as well.

Sometimes people ask, "Who gave you the most encouragement about your child, and the most support for the new parent?" I would have to say, "This particular pediatrician."

I recall a story of the grade one teacher, the first couple of days that Marianne first went to school. Well she gave all the other children numbers to print on a sheet. I believe it was the number 4. And when she came to Marianne's desk, she gave Marianne a nice picture to color, because she wanted Marianne to have success. Her intention was honorable. I'm not saying anything about that. She thought Marianne could color but she couldn't do numbers. O.K. this was a low expectation. So Marianne looked to the left of her and she looked to the right of her and she saw both students with the number 4. So she took up her coloring page to the teacher. She put it down on the teacher's desk and she said, "Four, please." She wanted the number 4. So the teacher.. and she'll tell the story herself, was so astounded that Marianne knew the number 4 that she couldn't find the 4's page fast enough. She was astounded! And she said from that day forth, she said whatever the other children were getting in the classroom, Marianne got too.

There's been friends that have been supportive, girlfriends of mine. When Marianne was really young and still to this day, they are supportive.

It's the five of us. There's not another person that comes to mind that I'd jump in and say well they really helped us out in the bad times.

Our pediatrician is a good support for us. Unfortunately he's retired so that's a big loss right there to us.

I know the first year that she was in school there was some parent that had spoken out from the very start of the school year at the "Meet the Teacher Night" and said that they thought it was an excellent idea. That this child be in the class room and it's high time it happened too.

I had a meeting with them and it seems to be superb. The classroom teacher has a T.A., again, so we seem to be getting luck that way... And the grade one teacher was more than willing to keep her the second year... would welcome the idea and she thought that she could get her to progress a little bit further

academically than if we plunked her into the grade two at that time. And she was right, in that.

I think there's a difference between listening to somebody and hearing somebody.

There was a lot of people would phone and a lot of prayers were said and masses were said and things like that. But there's a difference between support that happens to be just given verbally... but there's nothing wrong with verbal support. You need that too...

She has different attitudes but yet the same discipline of speech and language pathology, (she has) a different way and a much different way of working with Marianne.

Spousal Support

And another good thing, when it's a couple doing it. I mean don't get me wrong, there's times when I'm burnt out wanting to wash my hands clean of it all... But then if you have that extra strength coming from the other side that wasn't so involved in it, that could then take over, so you get rejuvenated again in order to carry on with the task that needs to be done.

...If I'm tired here in the evening and I've had a particularly bad day with her after school, I just can't take anymore... that's it. I'm done. But, see, then Sam can come through the door fresh, "Now what's the problem here?" you know. But he hasn't been in it for the last two hours and it's an entirely different situation.

Sam's usually home now on craft night. He knows that's pretty important for me, craft night.

Siblings

I would say the oldest fellow, like I say, was three and a half when she was born. I can remember distinctly him saying, when we brought her home, that he thought her eyes looked different. You know they have a down, a little slant. I remember him saying that. I would say he was a good five, before he started to realize the difference.

Marianne would have been a year and a half, and he knew of some other children who were her age. But you have to consider he could see, at that time, that I was doing a lot of extra things that you just don't normally do with a baby. I was doing physio-therapy. I must say that both boys, though, have never ever shown any kind of resentment or anything like that towards her. The youngest fella was only eleven months at that time. I think he grew with her, not being that far apart in age with her... I don't think he ever really realized that there was too much wrong with her. I think he just went witn the flow of things. Definitely he saw, too, that there was some extra work being done, and things like that; but I don;t think... Of the two boys, I would say the youngest fella would be the least likely to be able to point out any big areas of disability with Marianne at that time.

It was hard on them I think... definitely. I think when you look back at those days, there had to be a certain amount that they lost. Yes. There's no denying that. But they are none the worse for the experience. I would take the oldest fella, thirteen now, and compare him to other thirteen year old's, that we know. I just look at the sense of responsibility that he has compared to other kids, and their general attitude to somebody with a disability or somebody that's a little bit different, our sons, they seem to have that extra thing that perhaps you wouldn't see in other teenagers that are so self-centered. Now I'm not saying mine are the best, they can be either. There are times when they get pretty darn mad at Marianne. You know there's no doubt about that. But over all, I would say they lost but they gained a lot too. I think that they've gained from the experience, as well.

I kind of wish that... of course you're always wishing... I wish that perhaps they would spend a little bit more time in the communication area where Marianne really needs people to use the sign and try and understand what she's saying and things like that. But then you look at other things they do with her, playing road hockey, etc. and they include her in the road hockey... So, you balance it all out. You can't ask too much.

...I would say by in large, they're fairly patient with her. They're very, very patient with her. I think, too, living the situation twenty-four hours a day, they acquire the ability to handle certain situations because they see how we handle them.

If it's a day that I just don't have the strength to deal with her stubbornness... And I just want to take her and say, "Come on!" and I'm losing my patience, everybody's patience is gone, automatically. I notice that... If I yell at her then the oldest boy will yell at her, "Come on get ready for school"... But the days that I'm not losing my patience with her and can handle it, then I see that modelled from them. That's how they handle the situation the next time she's in a stubborn, stubborn streak.

I think all in all, it's been a positive thing, but there's no doubt that they had to give all in some areas to gain in others... There's no doubt about that. It's not all a bed of roses. But I think ultimately what we've gained from these experiences, it's going to help them.

I've heard various people comment, teachers of the boys or something like that. Something, somewhere has made a big difference in them...

If there's somebody hurt in a fight, if somebody has a problem, it seems to be our fellows, not just ours but others too. But they principally go and handle the situation... And they look out for those that are being teased on the playground or something like that.

Of course communication problems is the one that's very outstanding for her. But if you were to question them on something else I don't think... they may say she's a little bit slower to learn or something. They certainly wouldn't go into it in any great detail. And it's not because they wouldn't understand it but that's the way they see it, I think.

Wayne has just left that elementary school now this year. He was with her then for the two years that she was in grade one. And I never heard a negative comment from him as far as being in the neighbourhood school. And, um, that began when he knew she was going down to Pine Hills school. Well, why shouldn't she? Where else would she go anyway but to Pine Hills?

One example of embarrassing incidents was last year. It was at lunch time. There were some kids around the grade one doors and I believe they were older kids in other grades. They were encouraging Marianne that perhaps she should take her shirt off... and then I think they, perhaps, were going to go further than that too. With all the clothes off cause they told her it was a hot day, that she should take her shirt off, which she did. She took the shirt off. Well I think there was a couple of buddies of Terrance who came and got him on the school ground, to come to her assistance. And he came directly over and got the shirt back on her and told her not to do that. Well, a teacher happened to be on duty as well, and saw what was happening. But Terrance did the handling of the situation.

He didn't want to disown her, which is what I got out of the situation, anyway. He didn't want to disown her, although he was embarrassed by it. There was no doubt about it. But he wanted to get to the one who really caused the problem... Well it's something strange like that. It's hard. It's hard on the siblings. He told me about that right as soon as he got in the car.

And then the older brother last year was in grade six. It wasn't that dramatic of an incident, I don't think, but uh... Marianne was in the corridor and she was running away from the teacher assistant or something. She was in one of her little moods there. She didn't want this teacher assistant and I guess she was making quite a bit of noise out in the corridor. She happened to be going by Wayne's room in school, and somebody in the school said "Oh, there goes your sister." So Wayne went out and he calmed her down. He handled it. He does that on his own accord. He will check in on her for a few minutes at recess and noon break just to see that she is happy doing something.

Characteristics of Family Members

I think they have a good sense of responsibility and a sense of humor, too. One probably has a good sense of humor and the other fellow probably doesn't have a terrific sense of humor, they kind of vary there... Sam's more of a serious type. He tends to be a little bit more tense in situations where I wouldn't be.

Relief from Stress

The service that I received at the day care was absolutely wonderful. I had no problem whatsoever. I reached out to the day care myself because I was at home with her. At that time I was doing physiotherapy. I was doing speech therapy, I was doing occupational therapy. And when I wasn't doing that, I was sitting in the doctor's office for an appointment, to the point reached in my life where I said, if somebody doesn't help me with something pretty quick, I'm going to lose my mind.

Strategies

Her frustration level was really high. Mine was really high because I didn't understand what the child wanted. So that's why we got into the sign language. We had a tutor come here who was deaf and mute.

We immersed in sign language right away. Because the tutor communicated only in sign. It was a real good way to learn because you had to learn to sign or you didn't know what the tutor was trying to get across.

One thing I don't do and I would say Sam, too, is we don't ignore. We don't ignore things. Certain things that she has done or tried to do which were unacceptable behaviors, we never ignored. We corrected unacceptable behavior right away.

I usually set a goal and stick to it. But always try... to use a reasonable approach. Not always a confrontation.

I try to work around them. I feel I have done that in my situation at school. The principal is not supportive of the endeavour of integration, and is just not going to be supportive. In my way, I worked around him rather than through him.

I'd say we're pretty good at family communication, but I wouldn't say we got it "aced" by any means. I think the boys are very good to say to you what happened or that such a thing went wrong today or something like that, which is very good. Sam and I would talk when we have the opportunity, such as when kids are in bed for the night, or when doing dishes, and so on.

I always keep Sam abreast of what's happening as far as any problems at the schools or things like that. So that he's well aware of what's going on...

I don't think he gets the feeling of being left out .. I think if anything, he would try to help out in as many areas as he possibly can. Sometimes I think he thinks that he's helping most by looking after what the boys are involved in, you see.

I'm knocked down an inch... But give me this breathing time until I get myself back on my feet here... I do that.

We swim over at the hospital pool. We (Marianne and Anne) go once a week. The kids love it and then I have a chance to talk to the parents while (we're) in the pool... I like it. It's good for both of us.

Well I'd have to say that (our ability to deal with family problems) over the years is good and nothing's really tumbled us... So I would say it's moderately good. Of course there's always stressful times... following something like that or if you have to deal with an illness. Or a lay off or anything like that. We certainly don't go off the deep end or anything and be totally crushed... or hit the drugs or alcohol or anything. So I'd say we do fairly well in coping with problems.

The basic philosophy I've always had with these professionals is I watch first, their reaction to her, and then I could find a base from there, where we're going to go. Whether it's going to be a success or failure. And so far I've been pretty well on. If the professional person, (as I arrive with Marianne) is "How are you Anne" and everything like that and there has been absolutely no mention whatsoever of Marianne being there or looking at her or anything like that. Well, that to me, says it's just not going to work out. If they acknowledge her and make her feel the least bit welcome... Because she knows who's friendly with her and who isn't...

Interface with Community

But I did have her in an art class down here. I did that for a couple of years. I met both positive and very negative reactions to that... Some from other parents who were taking their kids into the art class... In fact one parent said to me one day, "What do you think she's going to learn here at the art club?" I said, "She's probably never going to make what your daughter can make. But she's getting exposure to other children and the children have exposure to her and hopefully those children will grow up with a better attitude to the handicapped than you are displaying right now!

And conversely to that, now, I registered her in the skate club figure skating program here. Now they gave me no problem whatsoever as to try and get Marianne into that program. None. Now, I know I make it clear to them at the time that you're not going to make a grand figure skater out of her. She hasn't got that kind of co-ordination. But she likes to skate and she likes to be with other kids. And I'm paying my $89.00 like my neighbor can pay $89.00 and she's coming. And I had no problem at all with them.

I'm going to have to give the church a whirl, for example, again. Because ah, I want her, now, to make her first communion. But the problem with the communion.. I don't think it will be the two priests at all. It will be just that she probably won't want to take the host. She doesn't like taking something new that she hasn't had before. But that's another one I'll have to go through again.

Changes that give hope)

But the support that actually requires an action... to actually go out and do something... Is a whole lot different.

If anything that I have learned out of this is that if anybody came to me and said they have a new Down Syndrome baby, the first thing I would offer would be tangibles support... Like if you want to go shopping on some particular afternoon, you drop the child here, and I'll look after it. That type of thing. People need that and there's not an awful lot of it.

I hope I see that (less societal ignorance about disabilities) in my life-time, I really do. Because, that is our main basis for... Our main philosophy behind integration, is that these other children will say when they are grown up and out into the work force, "I know someone who had Down Syndrome and things are not as bad as what you are trying to make them out to be."

It's great to see this new material. Video's too that are out now... Give Me A Chance. Things like that. The child first, I'm a baby first... that type of thing. It's what we needed.

Education

Well in her day care years, she progressed through the day care a little bit. They could see that the oral language just wasn't coming. They did ask me if I was interested in sign language. Well I knew that the child needed a mode of communication.

The grade one classroom that she was in with the regular teacher and the teacher assistant signed to the class. They took it upon themselves to teach sign language right in the class room... Ten minutes a day was allotted to sign language, to the point that those children at the end of grade one were almost fluent in sign language. They amazed me how they picked up and they loved it. The same thing is carried through in the grade two room but that's only at my insistence that it be continued. They did want to drop it. They figured if they forced her to use oral language that maybe that's the mode. But there's no sense in forcing her. She depends on her sign and I think you have to learn this stuff, it's as simple as that... So don't take away from her what she's got. Keep adding to it... don't take away what she's got, is my philosophy. So they do the signs.

I'm trying to think of something other than the formal education but as far as community events or participation in activities or anything, it's usually a family thing that we do. For instance we all go to church together or something like that. Or we're attending hockey games. Education as far as day to day living for Marianne is a joint effort from all of us, I would say... because we all participate in that. But the formal education I would say it's more.. it's me, as far as what she's getting in school and hoping to accomplish and things like that.

Wayne did go out. Of course the teacher in Wayne's room was very good, too. He didn't mention the fact that Wayne went out or anything and had to help with his sister... He just... If he felt Wayne had to do that, he let that go.

Oh day care was excellent. They had a good group of people that were very knowledgeable; but yet, didn't shove they're knowledge down your throat. They didn't always want to make themselves look like a professional telling you what to do.

Although you knew from the very time that they opened their mouths that they knew what they were talking about... But they always... they could spill off a lot of things to you. But they would always say, well what do you think? Like they gave you chances to participate.

And they always kept you abreast of... "Look that's not working. We're cleaning the slate on that. What we're trying to do with her is not working. It's probably us or the way we're doing it, or something. But we're scrapping that and we're going to try another whole approach on that."

And they didn't try and take her and stick her into their system. They kind of made their system work around her.

The speech therapist I have now is Susan Jones. She also knows the things that we need for Marianne. Susan wanted to have her the first part of the year down at Pine Hills school so she could help get the program in line with computers and things that... I have an awful lot more of personal effort put in from the therapist as to try and help out with Marianne's communication from Susan... She starts with a positive. She's not going to build you up with a lot of stuff that you know is a whole lot of bologna, that's for sure, either. She starts with a positive and works from there, rather than the negatives.

That's, I guess, why I got along so well too with the grade one teacher that had her for two years. She was positive. She would always show you, well look she did this and she can do this really well. We are very pleased with her ability in this area. And then (as the teacher progressed) she'd say, "But, of course, you know, math skills, she doesn't have those yet and maybe she won't." You know, that type of thing.

Gradually come down and got out everything she had to say but she didn't meet me at the door and say, well look, she can't do this and she can't do that. It's a whole different approach.

CHILD

Child's Characteristics

O.k. He's curious, and he's funny. He has a good sense of humor. And he's nice looking, you know... pleasant.

He was hitting and slapping and screaming and things like that...
He's frustrated. He's very frustrated. He doesn't have the language to be able to express what he wants to say. And he will become quite frustrated.

Communication

Sometimes he'll say" Mom", if he hasn't seen me for a while. I'll come in the door and then he puts out his arms and say "Mom"...

He said "boy " and "good" and "out" and "up". He's got a few words but they are not consistent... One time he'll say them and then he won't say them for two months... Then he'll say something else, you know. He makes a lot of noises he's being very vocal... So he's getting along excellent.

Well if I ask him to come, He'll come, or I'll say get up... simple commands, that he's responding to, "come", "up", and "let's go out", you know. I try to keep the language to things like, "shoes on", "coat on", "off", "in", "out".

Child's Play, Pleasure, Recreation

But she wouldn't get him to play Barbies with her or (ask him to) come to do something with her. She wouldn't.. The little girl next door... She'll get her to come play Barbies. But maybe that's because she's a girl and Shane is a boy, I don't know...

He'll usually just watch them. He'll watch them play. He'll come over and he'll look but... sometimes he'll put something in the middle of them. And she'll say, "Shane that doesn't go there" or something. You'll hear her... Or she'll growl at him. But he'll sometimes get his own things, too, and go and play. Or he will come out and hover near me.

But for Shane... He can't play appropriately with the toys. He wants to take a pen and put a clothes pin on a pen, or put a stack of things on top of things and try and fit things together, even things that don't fit together... It's amazing what I've got that's fit together for him.

He's always just fascinated with things that will go on your finger, that he can put on your finger. So you get things like

puppet things for his fingers. He'll find the weirdest things to try to put together.

If I put on some music, sometimes he'll.. Margaret will be dancing around there, Margaret wants to dance with me and I'll go and dance with Shane and Margaret. I'll have one on one side and one on the other. We'll be dancing around the living room.

There's uh, one thing I wanted to mention about him... that he has exceptional balance. It's unreal how he can balance himself on things.

Oh my goodness, we had a hospital crib with the great big high sides, and I kept him in that for the longest time. One morning I went in and here he was just sitting on the edge of the crib, just balancing. I mean it was only about that wide. Sitting there. Another time I went in a I found him walking. What was he walking on? The rail along.. He had climbed up onto the dressers, got into his crib and was walking along the railing of the crib. I just couldn't believe it. Then we have a ledge down stairs in the basement that's four feet up, and he walks on it. He walks on it all the time, I'm forever going down and finding him up there.

Learning/Knowing

Well, I know what's wrong, what the problem is. It's the attention. Shane needs praise and he needs it from me. The last month I've been doing a lot of praising but I've been away on a conference for five days and I just haven't been here to give him his praise.

Shane has to be praised... This is probably one characteristic on the negative side. You just can't say you did a great job Shane. You have to go "Oh! Boy! I really like what you did, Shane. Boy you're a really smart little fella" and then it's the big smile on the face. So you have to go overboard in order to get a reaction from Shane. That's why a lot of people find it hard to work with him. They aren't used to him, because you have to really give of yourself to get the reaction. But it does come.

And I also found out that I can over-prompt him in teaching him. That's a danger too.

Child's Friends

I found that, now, they accept him (at Sunday School). When he first came in he wasn't sitting down. He wouldn't sit down and he was yelling some and doing inappropriate things. And all.. the kids would laugh some and now it's o.k.. But I find that the kids... they're saying, "Hi Shane", and the older kids, will be walking along and they'll see Shane and say, "What have you got there, Shane? What are you doing?

They'll talk to him even though he doesn't speak back to them.

They will talk to Shane and Margaret and get things for him or do things.

Stress/Anxiety

General Parental Stress/Anxiety

I was pregnant around about three months and I looked like I was ready to go deliver. So anyway Phillip came down with me and they did an awful lot of measuring and I didn't know what in the heck was going on... The technician had said, you have to wait to see the doctor. And when the doctor came in he said, "Well, have you told them yet"? And I just tensed right up because I thought "Oh no, there's something wrong with the baby. And then as he turned around he said that we're going to be proud parents of twins. All I could see was bottles and diapers.

I just forget to say, "Well what do you think? or "Would you like to come?" (to Phillip). I never thought to turn around and say, "Would you like to come with me to this?" Or "Maybe we'll do it when we both can do it". Or "Lets set up a time." I guess I've just kind of gone out and done the things that had to be done myself. I find that happens an awful lot.. You get an appointment and you say, well I'd better take it because it might be months before that person's going to make it back here again. You can't just go any time when you want to, or when it's convenient for you. It's always convenient for them (the professional).

I wish that I had started right from the first. I wish that somebody would have said, hey you've got (to include him in). If there was some way that they could speak to you somebody in the family support program or something that would say, can your husband become more involved? How can we keep this a family thing? Because sometimes you just get so desperate in your struggles that you forget that you've got a family unit that can work together to get things accomplished. And use each other and lean on each other and that kind of thing.

Because you have the same kind of frustrations and stuff no matter what kind of a disability it is. You're still going to feel a lot of the same feelings... Frustration in getting your child into school or getting the proper supports and that kind of thing.

Sometimes my mother makes my life stressful. But who doesn't have... it's just that she sometimes.. she used to... She used to frustrate me an awful lot... I've changed. I am more accepting of people's differences.

Oh back three years ago it was extremely stressful. I lost all self esteem. Oh, not all, I must of had a little bit of self esteem to get me into Al-Anon...

I was just like everybody else that lives with the disease of alcoholism. It just effects the family in that way. The wife becomes wanting to control the situation. She feels that she should do something because this person is out of control. They're spending money that they don't have to spend. They're becoming aggressive when you go out to dances and things like that. You can't enjoy yourself. You feel that people are.. that people are holding you responsible. And a lot of people will hold you responsible. They'll say "Can't you do something with that fellow?" or that kind of thing. I laugh when somebody says that. I say "no, but can you? Go right ahead." Now I can be much more calm about it if Phillip's acting like a jerk. That's Phillip. That's got nothing to do with me.

I said, "Well, that's Phillip". If you have any suggestions that you want to go ahead and do, go right ahead." But it took me a long time to get to that point.

I realized that this person was a sick person. They weren't just doing it to be mean to me or that they didn't love me. I know that Phillip loves me very much.

And I know that Phillip wishes for anything in the world to be able to be normal. To be able to drink like everybody else, because he see's all his other friends going out and doing it. And he say's why can't I? And he doesn't understand.

I understand the fact that when Phillip drink s alcohol his chemical reaction set's off a craving like opium would.

And so it's very addictive. And so I understand a lot about the disease. I understand more about it than Phillip knows about it.

I know that with any disease, there's going to be the side effects from it, or the symptoms. It's common in everybody that's dealing with this disease. I look at it as the same as my eating problems. I eat because of a lot of reasons, because of my frustration, sometimes, in not being able to cope with things, like with Shane's disability, and I felt that there was a lot of pressure put on me to do everything. That he (Phillip) wasn't taking responsibility and so I was resenting him. So I would eat, just not to feel. So I can see with Phillip, how Phillip copes with his frustrations is to drink .

I find Margaret more stressful then Shane... Because she is very demanding. Like she's um, oh I don't know... It's always Mom, Mom, Mom, Mom, Mom... To get my attention. It's just like, it's almost like.. I know she needs my attention but it's like I don't think I can give her enough.

Oh I had some friends... I've gotten rid of them. I used to be there with my ear open and just letting a lot of people drain me dry. And I just said enough is enough. It was just that.. I just said look, there's a place where you can go and get help. I'm not going to be your program. You are in a program, a twelve step program and I think that maybe, it's time to start using it. I had to be cruel to be kind. I just couldn't be listening to people phoning up and going on and on and on. They didn't really want to help themselves, they just wanted to have something to cry about. So I said when you're ready, when you want help, I'll show you how I did it. How I made it through but not until you're ready to want to do something about it. I don't have time for it. So I don't get these phone calls anymore.

Illness and Stress

I said this to the doctor that he's having what seemed like nervous twitches or jumps. He didn't really say much about them. I was getting concerned because they were happening quite frequently. He wasn't sitting up by himself. I had to prop him up and stuff like that. When he took a seizure I noticed that his eyes were going back in his head, then I knew he was taking seizures... As soon as I mentioned the word seizure to the doctor, that's when things started to happen... We took Shane to Dr. Wills here... We have a pediatrician in Midvale, Dr. Kelly. I had taken him to Dr. Wills and uh, he was then transferred right down to Dr. Kelly. He had been seeing him before about a heart murmur. He was checking him out for that. And I mentioned, I think, about nervous jumps to Dr. Kelly too; but nobody was paying attention. When I wasn't calling it seizures... Nobody was paying attention. Even from the first, I felt kind of frustrated in that... Nobody was listening to my concerns about Shane.

Anyway, they took a "cat scan" and E.E.G.. At that time they thought it was epilepsy. They gave me some information on epilepsy and we went home. We started Shane on Depekane. Anyway the Depekane... it didn't take the seizures totally away. Before medication.. When we took him over he was having about 134 petite-mal seizures a day.

He's fine. Now there was a period in his life while he was on Depekane from five months until about... That was in December when I first put him on Depekane until about October or November, somewhere around then... that he didn't do anything. He was intoxicated on that depekane and we didn't know. The doctors were saying that it was his disease that was causing him not to be sitting up, not to be crawling, not to be doing all this stuff.

But we've done a lot of trading medications around and sometimes I've felt like he's been used as a guinea pig, to try out medications. But I guess that's the only way that you can do it.
Believe me, I had such a hard time I was scared before, that something was going to happen to Shane...

I always felt there was something holding me back from totally loving him the way he should be loved... It was like, I don't know. We couldn't make that communication. There just didn't seem like... Him and his father seemed to be quite good, you know. They bonded together quite good. But we couldn't seem to make that connection. I'd hold him and everything... I had a real problem with that. because I felt that something was holding me back... I think it was the fear that something was going to happen to him, that he was going to die. I didn't know what I was going to do.

We went back again for the second time. It was then he was diagnosed. They wanted to try a treatment called, A.C.T.H.. It's a steroid. And I had to give him needles. I was petrified of needles... Well, they wanted to teach me how to give needles. I thought, oh, o.k. if I'm going to have to do this, then I'm going to have to do it. So I learned how to give him these needles and it was just.. There was a period there for about two months that it was just a nightmare.

I'd give him these injections. He was screaming all the time... The A.C.T.H. made him hungry all the time... It was really, really rough.

Stress (Work/Job)

It's just... I'm trying to spread myself around to everybody. Especially when I've started out to work like I have... Maybe I should have waited a little bit. I find it very difficult right now to be working and to do all the things that I feel that I have to do. There's just not enough time. There's not enough time for me. I'd much prefer if I only had to work three days a week. Because I'm finding that... It's just that sometimes I have to work because I need that. I need that connection with the outside world. I can get depressed if I'm home twenty four hours a day, seven days a week, that kind of thing. You can just get too depressed. I need that contact with the outside world. But I sometimes feel that I'm cutting myself up into too many chunks and not giving enough to everybody.

Illness and Stress (Financial)

We took him down to Dr. Kelly and um Dr. Kelly said that he was taking infantile spasms... And that it was an emergency. He had to be taken over to J.B. Hospital right away. It was just all of a sudden. It was Dec. 5th, I think. And he was only five months old and we went over to the Regional Centre... I found it very frustrating at that time, too, because it was just around Christmas time. Financially we didn't have the money to go. Everybody that time of year has done Christmas shopping. I had done my christmas shopping and I just didn't have the funds available to me to go to the Regional Centre... Anyway I was lucky in that an aunt lent me the money to go to the Regional Centre. I had to stay over there for a week.

Demands on Parents

A lot of his behaviors are autistic... austistic like behaviors in a child with tuberculosis.

He wasn't coming up and making the connections with me. Telling me "I want you". Or coming up and sitting on my knee or doing all that kind of stuff. It's just been ever since I took the cars... And I had to do funny things. He'd run around the room from one end to the other and I had to run around the room behind him and if he'd put a toy into his mouth, I'd put a toy into my mouth... And I did this for a while just to get into his kind of world. It was so funny. I'll never forget one day he took a car and then put the car in his mouth. I went and took another car and put the car in my mouth. He turned around and he looked around and all of a sudden he realized that I was imitating him. And he started to laugh. Ever since then it's been great. We just have a natural way of communicating and that just makes all the difference.

Sometimes he'll be off in a stare. I just tell him that he's going to be o.k. and say now, just relax.

If you're accepting of him and you take the time to show him that communicating and language is important when he's vocalizing. I try to turn it into a word and I communicate back to him, to show him that talking is fun... That we both need to talk back and forth.

I suppose it's not fair to say that I don't feel stressful with Shane. Because there's a lot of demands with his frustration and his communication problems. Two days ago it was like... He was just yelling and hitting and I couldn't do anything for him and I said, you know, this is just getting right back to where we were before.

And I hadn't been using the "time out" because things had been going so smoothly for the longest time. I just.. well enough is enough. I just said, Shane no more throwing, no more hitting, you're going to "time out" and I put him in "time out". And since I did that, then things are back to... he's getting back to normal.

Services

Social Services/Day Care

I have done the fighting to get Shane early intervention because both me and Phillip were not working at the time. I fought for nine months to get Shane's day care costs covered because we were both not working and weren't requiring day care, we were requiring early intervention...

They were saying no. And finally, what did they end up doing? Using our respite care to pay for the cost of his day care. So for forty five dollars a day that's what they'll give him for respite care, I can buy three days of day care.

I spent nine months and I went right to the top in Social Services to get day care covered so that my child could go to day care. And in the end, the answer was so simple and so much easier. Through Family Support you are entitled to 21 respite days a year which is 63 day, day care days. Sixty three days, compared to their twenty one days. You know like, give me a break! The answer was so simple and yet they made it so complicated for me. Nobody would say, "Well let's do this". It wasn't until I fought and just kept being the squeaky wheel all the time that I finally got somebody to put on their thinking cap and come up with a solution. Cause I was saying, I want a solution. And I don't want it to be too late. Right now, they have a waiting list for tutors. They can't provide the tutors for the day-cares. Kids are waiting and there is no priority list. It's just first come, first serve... it doesn't matter if your child is severely disabled or whether the child has no disability or they just feel that he would benefit from tutoring.

The System

If you were with a bunch of professionals, if you're dealing with a lot of professionals, you do feel like you're on the one side and they're on the other side. And to be able to sit around in a group of parents that are going through the same things because they have a child with a disability... It doesn't have to be the same disease or anything. They still go through the same frustrations or the school board's not accepting your child and you'd like to punch the principal in the mouth! You know, that's a real...feeling. And a lot of parents get guilt feelings about that. You know about getting that mad, that angry.

Services/struggles

There was the time that we went to take Shane to see that developmental psychologist. She handed us a book of all these things. She asked me why I was there and I said because I wanted to have an understanding of Shane, where he was "at" so that I could know where to go from here. Anyway she did an assessment on him and then I asked is there anything... could she give me anything that would help? That was my main purpose of being there was to get some information. Pass some information on to people... But she handed me a photocopied... Well, she didn't hand it to me, she sent it in the mail to me. I was really thick, and it just had... it was more of a clinical kind of... something that a professional would use, not a parent. I mean, there was a lot of things in there that I didn't understand even. And when I got it, I just put it on the dresser and that was it. I left it there for quite a while. Then I thought.. every time I walked by it... I'd get the guilty feeling that I should be doing something. I should be working with Shane and all this. And then... then I'd say, oh well, I just

don't understand. Anyway,... every time I looked at that thing I felt guilty because I wasn't doing anything with him.
But I just didn't know how to go about doing it. It was the same thing with the speech pathologist. She gave me the Hanen Early Language Book and said, "Here, do this". And I just looked at it. It was a binder and it had a lot of information in it. You just can't do that to people, just go and hand them something and say do this... And not go over it with them and show them how it works, or how you can bring that stuff into you everyday life. It just felt like it was too much. It was going to be too hard to get the information out of it and it was going to take time from Shane (just learning how to do the stuff)... Anyway, I just would feel guilty about not doing it.

This is only one person. There's a lot of other people that are involved in this child's life. It's not just the mom and giving the mom all the stuff. If you want to go and make something work and work effectively, show the whole family how to do it. Show the siblings. Show the husband. Show the grandparents. Call in everybody.. If it's a speech pathologist call in the family. Go to the family setting. Go to the home. Show everybody, not just mother, because there's other people that probably have a better natural ability to do it. Like my mother, whenever she sees Shane she can be using the same kind of skills. For instance, language... keeping your language level to short words and short sentences. So that he can understand.

That's something that just telling me isn't going to make that big effect. But if you told me, my husband, my brothers and sisters, my mother... my husbands family. If we got together like me and Phillip and then had a way of letting the other people know by a video, or something, that they could watch. Because the family, the extended family doesn't know how to help out.

Now the speech pathologist that Shane was working with first, she had no clue how to communicate with him... I could see that in their communication. And it was a waste of time. Because she just did not have the skills to work with a non-verbal child... Now she was good with children that had speech already. But when it came to the non-verbal child she wasn't any good. So I wrote in and requested that I have another speech pathologist because I felt that the speech pathologist that was presently working with him... I didn't feel that she and Shane interacted that good. I felt that maybe, non-verbal was not her area of expertise... I got a new speech pathologist. I was down in the Capital City and I was talking with the day care, with the head of the day care. Fay Clark, the head of the speech pathologists, she said.. Is that Sara out there? And I said yes and she said I've been meaning to get a hold of you. I've been trying to phone you. She asked me to come into her office and she wanted to know just what it was that I didn't like about this speech pathologist and that the speech pathologist was very upset with me. She took it very.. like on the defensive. And I explained to Fay, I said it wasn't that I didn't think she was a competent person. I just felt that her non-verbal skills weren't... the skills that she did possess weren't enough for Shane... I wasn't putting her down. I was just requesting that I have somebody else that I felt would be much more suited. There was other speech pathologists that I knew were available so... I didn't think that it was going to be a problem. But she was quite put out that I had written in a request so... If she had a problem with the letter she could have called up and said, "I'm just wondering why you don't feel I should work with Shane", or maybe she could work on getting better with non-verbal kids... And I did it in a way that... I made sure that it was done in a way that wouldn't put her out. I wanted her to know that it wasn't.. that I wasn't putting her down as a professional... I just felt that Shane had more needs than she could address at this time. I didn't mean to offend her or anything. Anyway, I know that I did offend her because I saw her in the store after that and said hello and she just turned her head and I know she heard me.. Sometimes those things happen and you'll be o.k. (in the relationship). But if I wouldn't have done that (wrote the letter), then Shane would still be with the same person and I would still be having that frustration that I was having before.

Education (Parental Involvement)

I think I find that one of the draw backs is that it's not done with the whole family.

Well I found with that program it was just me and Shane going to the course and if it would have been somebody coming into our home and showing us how it would work, in our home...

More than taking him out of his home. I think there needs to be more of how you can use the family strengths... the things that are in the family.

You need to bring everybody together because people feel left out. It's hard to do once you learn a new technique and once you do it, then it's hard to teach that other person or bring him in. Like with my husband because he wasn't physically able to be there when Shane was diagnosed or at the hospital and stuff like that, it makes it extremely difficult to draw him in. It's just so hard once you get into a pattern of doing things with your child and taking responsibility. It's hard, then, to go and say, "Here could you do this?" I like to keep the structured play over at the day care. At home I like to have the natural, normal environment of learning, like getting dressed... And things like "Put your arm through" letting things happen, naturally. We're all trying to do that. The three of us let Shane do it. Or we try to remind each other to show him how to do things and help him become more independent.

We're going to be getting into a clothing "program". It has to have the cooperation of all of us because Phillip has the children between four and until the time that I get home.. Phillip has to make sure that he takes him to the bathroom.. We'll be doing this (the clothing "program") with the day care. We're setting up a case conference now with the goals for spring and for the fall. What is our short term plan? What are our long term and short term goals?

Personal

"Dad"

No, my husband picks them up because they get off, Shane gets off at four... But he's great. My husbands great as far as I mean, he has supper ready. It's ready when I come home. And he's really good with Shane. He's... I don't know, he's got a lot more patience than I have.

And the kids, they just... they really love their dad. And he loves them.

I feel that he probably does feel left out because of the training I have in the field. Now I'm taking my M.R. (certification) and I've got all this training and I'm a member of the Society and have been very active in that both at the local and provincial level.

I've been very involved in this and it's... The gap seems to be broadening. But he provides the support though, too, for me to be able to do things. To be able to get out.

I don't know whether it's that we've reached a point in our relationship where it's hard to know what to say... Because I don't want to make him feel that I'm blaming him for not becoming involved.

It's hard to extend the hand and ask for help. If I would have involved him right from the start, but you see, I didn't realize...

If he's not working. Sometimes I'll get a baby sitter but mostly he'll do it. Mostly, he supports me in baby sitting. He'd come with me to the meetings and stuff like that if I wanted him to come. He'll be there. I don't know how much he'd say. But he would be there.

I think it might of.. it probably hurt his pride that he couldn't provide this himself. And he wouldn't go.. he wasn't about to go to people and say, "Look, we can't financially"... because I think it had a lot to do with the fact that, that would make him have to look at his drinking problem, too. I mean, it's not that he was drinking a lot and spending a lot of money. But he was still doing it. And I think it made him really realize that he was having a problem, and that his disease puts the extra strain on our family.

Phillip is really good for me because Phillip's... I'm the type of person that jumps in. Phillip's the type of person who will say, hold back a second and let's look at this.

He was the one that discovered that Shane was intoxicated with that medication. Because he said he was looking through our photo album and he said, "Sara, this is not the same child that we had before the medication." I said "what do you mean?" He said, "come here and look at this." We had forgotten what he was like before he was ever on the medication. I was looking at the pictures of the kid smiling with bright eyes. I said "You're right." He said, "Well, what do you think we should do?" And I said, "I think we should.. we've got to get him off the medication or something. Phillip was the one who suggested that we take in the photo album with us when we went to see Dr. Curley.

Phillip will be out in the garage and Shane will be out in the garage with him. And the two of them will be just puttering around. Shane will be doing his own thing... Phillip doesn't get him to do a lot of stuff but it's just that they're there together outside working in the garage. And Jill too. She'll go out too.
Phillip helps them with dressing and stuff like that. And he's so proud of them too. I mean, whenever he does stuff with them he really praises them. And Shane is real pleased. So Phillip knows the importance of praising. That's how he's supportive in those areas. He really... he is a good father to them. Phillip has his problems but he's a real good father to them.

Mother's Personal Needs (or Mother's Parental Needs)

I wanted Margaret not to feel that all my time was spent with Shane. I knew that I needed help in order to make the balance so that I wasn't giving all my time with Shane and not Margaret... I realized that in our family we're going to have to have that extra support in order for us to make it... So I started taking him out to a lady's place just a couple of hours a week. Probably two

times a week or something like that... Let me see, how old was he? He was about two when I started taking him out.

I'm a firm believer of acknowledging the need to get away. Parents can't be everything to their children... You have to look outside. You have to get the supports that you need. If you can't get them within your family, you have to get them somewhere else. And you have to be realistic about things. I just felt that in order for me to stay healthy, that I was going to have to have some time to myself too. So I'm very much a firm believer in respite care, in having somebody to help.

Sometimes I get frustrated because he's at that stage where he's pushing, independence. Push Mom away. He doesn't want any hugs right now, and that kind of thing. But I still want to hang on to him. I just want to hang on to being close and stuff like that, cause it's, it's just been so neat. Cause I didn't have a lot of connection with him when he was younger.

That's dealing with the family thing. The everyday things that are different. The fears that we are different. The fears that we have inside and stuff like that. We don't talk about those. I find that one thing I would like to have is a support group for parents that are saying, you know, when their child has been crying for twelve hours straight that they feel like being able to say I could just take him and shake him... and make him stop. That's O.K. That's a feeling. We sometimes feel we are bad parents for feeling that.

That's a real feeling that a parent has when their child is screaming and you don't know what the child wants or they're pushing something at you and can't make it fit together and you don't know how to make it fit. The child won't accept the "no" and the feelings you have that go along with that. You can't help him. Where can you share that?

It's just to be able to sit there and talk about some of the things like... I don't know, just the frustrations of dealing with doctors or with anybody. Just be able to go and say I feel like every body's ganging up on me. How could they let themselves get that angry or things like that. Or just being able to go and say it makes me feel sad. I seen two kids running down the road and my son was standing in the driveway wanting to go too but nobody asked him to go, and how it made him feel inside... to have that happen.

At the conference there was a drama group put on a drama from Newfoundland. They did some skits and some singing on different aspects of what parents go through. It was about a half an hour or forty-five minutes within that time period. I went through about, I don't know, how many emotions. It was just like.. I was watching it and all the feelings came back that I had suppressed, because you don't have anyone to talk to about them. They all started rushing out at once and it was just like... I couldn't believe that I had, that many feelings bottled up inside me because I didn't have a place to really talk about them where somebody else would understand.

You can talk to your friends but they don't understand the way another parent would understand.

Ya, I think if we, all (the various groups) got together and just said let's have a group of parents just a place where you can go... start up this group that's totally different from the Society and from the other groups... Just a group where you can just go and "share".

No, no, I blamed myself for not doing it, not taking the time to sit down and read all through the information and uh, you know. Because I just didn't have the time. I was dealing with a lot of problems. At that time I was dealing with getting myself sane again. I just didn't have the time to just sit sown and sift through a lot of the information and pick out what I thought I could use. I needed somebody to tell me, here's two or three things that you can do at home. Maybe not even three, maybe two things that I can work at and then try something else. But don't be giving me a whole bunch of stuff that I wouldn't know where to start with... It's not that I don't feel that I'm an intelligent person that could have gone through it and picked out the things that I needed to do. But I just didn't have the time to sit down and figure it out. Not when you're getting it from all different areas, it just can be overwhelming.

I have a sister, she's the one that works down at the flower shop, while I'm down there creating, I'm down there talking away to her... She's more like a mother to me... We had a big family and the older girls had to help out with the younger kids. So we've got a very special bond. She's my best friend. We share a lot of things. I can tell her anything. I know that it's not going to go beyond the walls... She's an excellent person. I feel that I'm a good friend to her, too.

I have another friend that's in the community... That I can share confidences with. She shares both the living with an alcoholic and the compulsive eating disorder. So I have a lot to talk to her about, too. Those are my two main people that I know that I can share everything with.

And then my brother's girlfriend, too. She's a good friend. She's the person that I go out and have fun with... the person that I can let down my hair and just, you know, act silly and talk silly. So I have different friends that meet different needs. It's nice if you can have somebody that you can share it with. Because even though it doesn't help you get rid of what you're carrying, it helps a person to relax about it and put it down for a little bit anyway...

I know that part of me, part of my personality is that I have to say what is there. I have been so used to stuffing things down, stuffing feelings and stuff like that. But I have to get them out. I have to have somebody to talk to... That's just part of me. If I didn't voice the negative feelings... like I'm a very black and white person as far as judgements on myself. I can be very harsh with myself. That's why I need to do it. I need to get it out because once I say it then I'm not as judgmental as when I'm thinking it. It's different. But at least I know that, that's what I have to do.

Care of Self

Well, as I said before it's my rest that is important to me. I will get a baby-sitter to come in... What I try to do is try and manage my time. For instance, spending time with the kids and planning myself around times when they're asleep. If I can possibly do that... But there are other times... Most of the stuff that I do is in the evening. In the evenings around eight o'clock...

Mostly I spend time with the kids after supper and then get the kids ready for bed, and then my evening is free. That's important to be able to have that. I try not to get too many things booked in, in one week if I can help it. This has been an extremely hectic month for me because I've been away. Normally, (I'm not away).

If I'm not going out to a meeting, I'll curl up with a book. Sometimes I'll watch a T.V. program, but not a whole lot. Mostly I like reading books and studying. If I have any homework to do, I'll do it. Also, I like to talk to friends. I like doing that too.

I like to dance. My husband doesn't like dancing that much. He doesn't.. Sometimes we'll go out to a dance, just the two of us. But I really like to dance so I also attend Over-eaters Anonymous, too. I lost forty-eight pounds in the last year... It was great. They (OA) meet on Friday evenings at a quarter after eight. Once a month or something like that, a whole bunch of us will go dancing after our meeting at the club in Midvale. We'll stay out until eleven thirty or twelve or something like that... So I have a lot of fun with them. And I like cross-country skiing in the winter time...

Sometimes I do 3-D pictures... I need that. I know that. That's part of me. And so on a Saturday afternoon, after work's done up. I will run down to my sister's for an hour or so and just make something. She does all kinds of crafts and stuff at her flower shop. I just go down and I'll make something and put it out on her shelf, so she loves to see me coming. I have to do that... It's a creative side of me that needs to express itself.

Something that really makes me feel great is things like on the week-end you get to sleep in, in the mornings, and the kids will come into the bedroom. We'll all be piled up on the bed and they'll be giggling and laughing and rolling around. That's when our family is the closest... We all snuggle up in our bed and that really makes things special. And then Sunday mornings I take the children to Sunday School and I like doing that, too. I like being with them.

Volunteer Work

Oh ya, I really enjoy that (teaching Sunday School) because it's so great... I teach the Jr. High class. They really challenge me, my thinking and my creativity to keep them interested. They keep coming back every Sunday. I'm quite proud of that fact... Plus my faith has become a lot stronger too... I've kind of turned Shane over, right to God. I said "This disease is too much bigger than me. I had to turn over my fear of losing Shane. I felt it was much better that I love him than not... Then be sorry later on... So anyway, I realized those things, it's just made a world of difference.

Inner Strength

I am very optimistic. I know things will work out. It's just... you just have to be patient sometimes and trust in God.

Phillip lets things bother him alot. I try to help with those things. He worries a lot about finances and things like that. I don't. I used to worry a lot and I just found that worrying did no good. Worrying didn't work things out.

They're going to be there anyway whether you get sick and have ulcers or whether you

have a good day. I take one day at a time instead of living week to week.

Survival

Positive Support

...We stayed at the Ronald McDonald house in the Regional Centre... That was great.

It was a really good relief to know that we had some place close to the hospital, to stay. I had lived over in the Regional Centre before so I knew my way around. We went over. I remember we had to be over there and it was a snowstorm on the way over. My other sister and brother-in-law drove us over. So, there was five of us going over and we landed in the Regional Centre in the middle of a snow storm... All this fun stuff. Any way, we got there and we got tucked in. Shane saw Dr. Curley the next day. Dr. Dooley is just a God-send. He has such a good way about him. Everybody just loves him. I started with early intervention for Shane. I knew that he had special needs and I wasn't trained at that time.. I could give him the love and the support that he needed but he needed the expertise too.

I found out through Council that there was a family support program. I contacted the Dept. of Health and Social Services and they told me about what they did. A support worker came out to see me. She did an assessment on Shane and then we talked about doing some home visits.

I wanted to get some help picking the right toys and stuff like that. I'm very concerned about intervention because of their relationship, being twins. I did not want Margaret to feel that Shane was getting all the attention because of his disability.

Yes, Shane is going to school next year, to the elementary school that all the neighborhood kids go to... it's not that far to go. As far as the people around here and the kids, helping and making sure that Shane is o.k. on the bus and stuff like that, everybody is being really good. There's kids next door here and... there's people that will help.

It's really neat. I'm seeing things happen more and more. We were at my brother's place and Shane was cranky and crying and there was me and Margaret and Shane. My brother picked Shane up and Shane put his head on his shoulder, and my brother lay down on the couch with Shane on top of him. And the both of them fell asleep on the couch together. And I thought that was really, really nice you know... It was nice to see that my brother cared that much about my child to not let me always be the one to see

to Shane. He just comforted him. It was nice to know that there is other people that can comfort your child.

But Phillip's sister in Midvale is really good with the kids. She's so extra special careful of everything. She makes sure... I'll take them there for her to baby-sit them every once in a while. She makes sure that he gets his medicine on time. She's the type of person that would go right by the book... Because she's so capable I know that when eleven o'clock came, that medicine would be in my child's mouth. I know I don't have to worry about things like that, or if there was an emergency it'd be that she would have him to the hospital. She's just that type of person. I feel she's very capable.

I attend the Al-Anon program. I find I have a lot of support there, practicing the twelve steps of the program. Now I'm not trying to be the person that runs the show all the time. And I'm realizing that I don't have to know all the answers and it's O.K. to reach out to somebody else, and recognize that somebody else can help. That's what my coping is. When things have gotten too rough for me, I've talked to somebody about it. I talked it out. If I just can't handle it any more, I get some help. Sometimes in just saying what the problem is, just talking about it, narrowing the problem down to what it actually is... In other words I try not to make mountains out of mole hills... So I got a lot of friends that support me in that way.

Oh, he's quite O.K. with that (Sara's attending Al-Anon). It makes for a much better relationship because I'm not just standing at the door with my claws out when he comes home late. I hope that Phillip will find help too. The kids will always love their father and their father loves them and I would never, ever, go take them away from him. I would still make sure that the kids would always have their father. I would make some kind of arrangements for them to spend lots of time together. But for right now, as far as me and Phillip and our family, it's working out pretty good. But it wouldn't be that way. Not unless I had the support of a group of people going through the same thing.

My mother has always come with me over to the Regional Centre and given me support that way. She won't go and take care of the kids, the two of them together because she's not that well. She finds it extremely difficult. It never ceases to amaze me. The woman had twelve kids. Three died and... I don't want to put keeping the kids on her either. I try not to. Because she's done well to bring up her own family... as far as coming with me over there or just to talk when I'm making a decision about something... using her as a sounding board.

They've (grandparents) been there financially and they've been there to come in and visit the kids and bring them candy and provide the things that we couldn't provide for them. Phillip's parents bought them car seats, snow suits, boots. She always is there with something extra for the kids.

Our family strengths? Well, just love and acceptance. There's a real bond of love that... it's just from the knowledge of knowing that everything's going to be o.k. And I've always been like that myself.

Well, the Society has been supportive, both "Local" and "Provincial". And then there's the community. They had a benefit dance when Shane was first diagnosed.

I find that the day care... They're really great for making me feel that Shane is going to be integrated into the community because, they're so accepting. Also I teach Sunday School. I take the kids to Sunday School and when I first went, they wanted me to be in the class with chase, I said no. I said, I'll take a Sunday

School class because I've got to get up and be here anyway so I'll take a class and you fellows can teach him.

The family doctor is great with Margaret, too. I took Shane out there to make sure whether he had an ear infection or not and to see if his ear infection was cleared up. And Margaret coughs and say's "I got a cold, Dr. Wills". And he says, "Oh that sounds like a bad cough there Margaret, I guess I'd better check it out". It's so sweet. He realized that she needed to have a little check herself.

I know a lot of stuff. There's a lot of research that's done at the clinic. I've provided Dr. Dooley with information which is good for him. He knows as far as Shane goes if there's something that comes up with Shane... I'll say, well, could it be this or could it be that? and then he'll look into it and do the tests. He listens to me. Instead of just going and saying... We took the photo album with us. We said, "Look", and the doctor said, "This is not the same kid"! And he said, "We're taking him down off of that medication right now."

You see, the best thing about Elaine Rhodes, his one-on-one teacher, is that she's a parent of a disabled child. She knows. She sits in on case conferences for us and she'll say, after we get out, look Sara, I know exactly how you're feeling. All the stuff that they're saying. Everything that everybody was saying was their own little interest. Out of all the things that they say what do you really feel that we should work on? And then I'll say well, you know, maybe this... She's very supportive that way.

Sue Beck one of the speech pathologists in the Hanen Early Language Program, brought that book... that green book than the other speech pathologist went and handed to me... She brought that alive. She showed me how to integrate that into my life...

Sue Kinaschuck is the family support program worker. She has been an excellent support to me right through. She'll say, well that might be too much for me or she'll say, well are you interested in this? and she'll give me information... if there's a workshop or something... that she thinks I might be interested in. If I get too much stuff or if there's a whole bunch of stuff to look through, she helps me to look through it and the decision on what would help, as far as what would be the best. She'll say, we don't want to get you overwhelmed with a whole bunch of information. She helps me to sift through a lot of stuff.

Ya, ya. She'll phone up and say things like, I think it might be time for a case conference. What do you think? And I'll say, when was the last one? And she'll tell me. She gives me all the information that I need. She makes sure that I have it. She keeps me up to date on what's going on. For example, this conference, here, the Intervention Conference: she phoned me up about it. But financially I wouldn't be able to go by myself. She said don't worry about the finances part. She said, I'll work that out. You just see if you can arrange to get the time off.

Siblings

When she went to play school, she was very protective of him. And she had to sit by him all the time and things like that. I tried to explain to her. Shane has a lady that works with him at the day care... She has a non-verbal son herself. The lady has all the signs and she's excellent. It's just excellent. And Margaret's becoming more comfortable with giving up the responsibility to her.
So now Margaret's.. she doesn't have to sit beside Shane. It's like all those things are leaving her. So I think by the time she hits school age she will be able to.. I hop

to put them into different classrooms. And I hope she won't mind. So that she doesn't have to feel that responsibility.

She does not tell anyone. I don't know how she communicates with him but it's.. She'll just say Shane wants a drink or things like that... just, out of the blue... He doesn't have to be standing by the sink or anything like that for her to know what he wants. He'll use vocalization to request a need. Usually crying or going to the cupboard etc. She can just... sometimes I can't figure out why he's upset or something and she'll just have the answer, and I say to myself, "boy why didn't I think of that"?

It's not a lot of interaction between them. But then they'll have fun times. They'll clown around on the beds or something like crawling into each others beds and things like that. But when it comes to... with Margaret play is play and she's got her thing to do... But clowning around on the beds is playing together.

With Margaret, she is really good with Shane's disability, cause she'll let people know what's going on. She knows when he's taking seizures. She'll tell people that don't know... She says, "Shane is taking a seizure and Mommy usually just says, "It's O.K., Shane. You're going to be all right, you're just taking a seizure". Now, you have to let Shane know that he's taking a seizure so that he'll understand what's going on. She explains it all out... I've explained it out to her. But she will explain it all out to people that aren't familiar with what's happening with Shane. When he does take a seizure, she'll say, "It's O.K., Shane is just taking a seizure". Then she tells them, you know, all the things...

As far as his speech she's really good with that. She'll tell people, "Well Shane can't talk yet". But she says, "But he will. He will eventually be able to talk", or "He'll talk soon.

But Margaret's great, you know. She is a good model for him.

Strategies

Because there are some supports there for Shane and I want Shane to have that network of support. I don't want us to be the only support system that he knows. Because the one support system can break down. If you don't have the other things out there to keep things going then it affects his life, totally.

But what I've done since Margaret was a baby is every time we've gone over to the Regional Centre I've always taken her with me there too, so that she knows what's going on, too... that we're all together.

I noticed in the last year myself going and trying to include Phillip, because I've just automatically went right from the first... I took over and just did everything that was necessary and left him out. Phillip had never been with Shane when he had a "cat scan". Well, there was a time... Ive been there other times for "cat scans" and when he was having these behavior problems one of the characteristics of his disease is that you have to go and find things out if there's a change in behavior because of giant tumors that can grow in that part of the brain that affects behavior. So at that time I just said, "Now is my chance". I'll make sure I'm busy that day with something else. Phillip wasn't working at that time and I knew that he could do it. So I sent him.

Ya, even if we do have to go through A.C.T.H. I know, now, that the second time I got smart. I went and got a nurse to come in and give him his needles. And I got "emergency respite care" for somebody to come and stay with Shane while we got away... I found that when he was crying and going on, it was so stressful for everyone of us. We were just taking turns leaving the house all the time... Where if I can get someone to take him out somewhere and we stay at home or we can go and he can stay home. It's necessary at those times. You have to get away. You can't be around and you... you still have to feel like we're a family. So, therefore, if Shane has to go out for a few hours because he's being very, very cranky during the treatment. I felt it was necessary... And then when he came home, we dealt with it. But it was a rest. That's what it was for us and my family. But you learn. Trial and error. You go through the nightmare once and then you learn how to make it better the second time.

I don't let things bother me because I've made up my mind that things are going to work out. Things will get better and that it's just a matter of slowing down and not getting in too much of a rush. The answers will come. You can get frustrated but talk about it instead of keeping it in... That's the most important thing for me. You have to talk about it and you have to let people know what's happening with you, even if it's not good. If it's really bad you still have to let it out instead of keeping it in. I need to talk out my feelings.

I don't take responsibility for Phillip anymore. I think that the more and more that I slacken off in responsibility, the more that he looks at himself. He has to look at what's causing his problems. I try not to let his problems effect us as a family and make him feel guilty... It took a lot of struggle and a lot of realizing.

Well I feel that without the Al-Anon program I wouldn't have.. our family unit wouldn't have survived because it's just... I was doing all the same things that every other woman does when they don't understand. But now that I understand and he knows that I'm quite comfortable, I can live quite comfortably right now with the way things are.

But I also know that I'm confident, I got my confidence back. I'm quite comfortable in knowing that I can leave if I want to or that I don't have to stay in the situation. I've got choices and that makes a big difference.

So all in all it would be nice to have something like that (a parent support group). I realize that the most important thing is realizing that you don't have to do it all... Just because your child has a disability it doesn't mean you have to provide everything for your child. If I was going to look at it that way, I probably wouldn't have been able to cope, because no one person can take that much responsibility and be able to remain sane and well balanced and healthy... You're going to become insane, if you don't get the support that you need to make things work. I can't provide everything.

Well I just take a problem... You've got to distance yourself from it, emotionally. You have to get rid of all of the things that tie you to it and say O.K., this is the problem O.K.? And what's everybody's angle? What is everbody's interest in it?

Right now they're only giving my son thirty hours of tutor time at the day care and I would like to have more. But I'm not going to go and fight because by the time I fought to have it all done and put myself through all that aggravation the time would be up and he'd be in school... So, I'm not going to go through nine months of aggravation... There's times when you fight because you've got the time to do it. And you have to do it within that time.

I don't do a lot of work, one-on-one, with Shane at home. The reason why I don't do a lot of it at home is because I feel that Shane needs to know that there's a place to go to work and there's a place to go and relax and be himself. He doesn't have to work over at the day care and then come home and have to work here, too. Shane can be just plain Shane and he doesn't have to... He can have his own space.

I don't go and have it structured. I don't structure things at home. I do the things that are more just a part of our routine.
I find that it goes a lot better, because when I first tried to do the teaching, I had Margaret on top of me all the time, wanting to be there because I was working one-on-one with Shane. I didn't want to be always pushing her away and saying "No", I have to work with Shane". I realized right then and there that I was going to end up with a very resentful little girl. That wouldn't be good for Shane because she'd be resenting him and their relationship... Shane needs Margaret.

I talk to Dr. Curley about it. Any knowledge that I get about the disease or anything like that... Always I'm sharing it with him and the pamphlets are there for him to read. So I mean he, he pretty much knows.

By next month, I'm supposed to get in contact with the school principal. He said in the fall to get in contact with him, when I was ready to sit down. I'm having my case conference so that we can plan for the fall. Then I can say O.K. this is what we have decided that we are going to work on. One thing that we decided was the toilet training. He's having a psychological re-assessment in the fall. Of course they'll call me so they'll know just how far he is along in his development. I want the teacher to meet Shane. I've got some video tapes too and that's what I'm going to do is I'm going to do some taping of him over at the day care in his structured place... for the teacher, so that she knows what she's up against and what she has to plan for. I don't know how they want to set things up. I really don't. But I want them to know what Shane is doing now... And so, they can say O.K. I like this but I want you to do more. I want to let them know what's going on now and have enough time so that if there's something that we can change,lets change it before he gets to the school.

I was the chairperson for the Provincial Society Education Committee. I know all the superintendents of the School Units and the head of the Teachers Federation. I met them all and... I've met the Minister of Education and the Deputy Minister. And I know who the guys are that make the wheels turn. So they're no strangers to me. I know that I'm not going to have a problem in either one. Because as far as elementary school, integration is fine. I might have a problem once he hits Jr. High because they have a segregated class and once they hit high school it's segregated. But hopefully, by then, that battle will be won.

Middle school is six years from now and I'm not going to worry about it right now. I'm doing things to familiarize myself with the whole system and then I've got all the contacts that I need to have. It will probably be a different government in six years time. We don't know. I know how "the system" works.

More and more I'm realizing that we have to work as a family and not just one person doing all the things. So now I'm feeling much more comfortable.

By doing this (taking part in this research project), maybe the professionals will look at us in a different manner. I was explaining that to Phillip last night, how easy it is for professionals to forget that there is a family. That it's not just the Mom and the child, it's the Mom and the Dad and... And there's the brothers and sisters and the grandmothers and the grandfathers. It's the whole family and all the people that, the person is tied to... They all effect the child's life.

I go to Al-Anon to help me deal with living with the alcoholism, and I go to O.A. to help me deal with my feelings about everything. Not just the disease of alcoholism... my feelings about Shane's disability and my feelings with my parents and how I was brought up. All those things. They're excellent programs cause they help you look at yourself realistically.

You notice your good qualities as well as your bad. When you're doing a four step inventory, it's like you can look at all the good things that are a part of you and you can look at the bad things that are part of you. And you can make conscious

decisions that you want to keep this, but get rid of a lot of these... Acknowledging them is half the battle.

But if I don't continue to remind myself by going to Al-Anon meetings and reminding myself that this is a disease... you can slip back into your old way of thinking, that they're just out to get you. I continue to go. But I don't make every Wednesday night. But I will do some reading or something like that... I need that reminder every so often... that I'm dealing with a sick person.

Changes that Give Hope

But I took the speech program - a program on speech and language acquisition. It was like somebody putting a key in the lock and opening up the door... Because finally, I understood what Shane meant when he would come up and walk around me. If I stood up in the middle of the room, he would come up and walk all along the chesterfield to the chairs and go all around me... He'd keep walking around me, but I didn't know that he wanted me... It made all the difference. Because then I knew that he was trying to communicate with me.

Ever since he came off of the medication that was drugging him, he's just been growing in leaps and bounds as far as his physical and his mental development. Since he started into the pre-school program, it's been good. I had a psychological assessment done of

him a year ago. And he's gained in the last year, it was eight months.

I still want to get my degree. But it's going to be something that I can work on. I enjoy learning. It's just something that I can keep continuing to do. They offer university credit courses at the high schools near here...

I'm planning on picking away at my degree over time. There's no behavior specialists or psychologists here that you can take your child to when they're having problems. It really frustrated me that I had to go all the way to the Regional Centre.

We've gone through three series of the A.C.T.H. injections and that's kind of tough. It was two months the first time and a month and a half the second time, and about another month and a half for the third. But, you see, every time he's had those series, he'll go for a long period of time with no seizures. After the treatment the seizures are controlled really good and he has good growth and development. So it's worth it. Two months of misery, but eight to ten months of not a whole lot of seizures.

Education and Teaching (Positive)

I'm finding when I approach the school... the principal of the school, he seemed very supportive too... He 's wanting to get together to make some plans for Shane's entry into regular grade one.

Well the day care tutor's just great! Cause she's been there. She has a non-verbal child. John's four years older than Shane, so she's got that four years experience on me. John and Shane are an awful lot alike in their development. She's gone through a lot of things like ear infections with John. And Shane is the same, he has a lot of ear infections. So she knows the banging on the ears and the slapping... Just the things that go along with trying to communicate with a non-verbal child. She knows him really well and the way he reacts to things...

A lot of times anybody that's not so "in tune" might not understand that. Like working on feeding and toileting. We (the day care tutor and Sara) made a decision that we weren't going to work on the two things. At the case conference, they wanted to work on the feeding and the toileting both together. We decided that with Shane, the feeding and the toileting was too much with the communication skills that he was working on, too. It was just too much.

I feel bad about it, but the.. Society wasn't a help as far as the family goes. They'll help you to fight to get your child into the system or they'll put on the boxing gloves for you a lot of times and help you. I find that there's a lot of emphasis put on fund raising and not enough on family support. I know you have to go out and you have to work and lobby government and stuff like that but there's also some things that parents need directly too. Parents need to talk about their feelings and get hooked up with some parents that know.. Everybody's situation is different but there's a lot of common feeling.

I really think that there should be two parts to the local Society. You have the advocacy part and then you have the family support, just the coffee and the sit around and lets talk about some feelings...

They have the toy library at the Society, which is good, you know...

They loan toys out and that. And they have a lot of resource material that's available. But there really needs to be a family support part of it.

APPENDIX C

Questionnaires

Questionnaires from Dunst, Trivette and Deal, (1988)

1. Family Functioning Style Scale (Responses: Table 1)
2. Family Needs Scale (Responses: Table 2)
3. Family Resource Scale (Responses: Table 3)
4. Family Support Scale (Responses: Table 4)
5. Personal Network Matrix (Responses: Table 5 and Table 6)
6. Inventory of Social Support (Responses: Table 7)
7. Support Functions Scale (Responses: Table 8)

Family Functioning Style Scale
(Experimental Version)
Angela G. Deal, Carol M. Trivette, & Carl J. Dunst

Listed below are 26 statements about families. Please read each statement and indicate the extent to which it is true for your family. There are not right or wrong answers. Please give your honest opinions and feelings. Remember that no one family will be like *all* the statements given.

	To what extent is each of the following statements like your family:	Not At All Like My Family	A Little Like My Family	Sometimes Like My Family	Generally Like My Family	Almost Always Like My Family
1.	It is worth making personal sacrifices if it benefits our family	0	1	2	3	4
2.	We generally agree about how family members are expected to behave	0	1	2	3	4
3.	We believe that something good comes out of the worst situations.	0	1	2	3	4
4.	We take pride in even the smallest accomplishments of family members	0	1	2	3	4
5.	We are able to share our concerns and feelings in productive ways	0	1	2	3	4
6.	No matter how difficult things get, our family sticks together	0	1	2	3	4
7.	We generally ask for help from persons outside our family if we cannot do things ourselves	0	1	2	3	4
8.	We generally agree about the things that are important to our family.	0	1	2	3	4
9.	In our family we are always willing to "pitch in" and help one another	0	1	2	3	4
10.	If something beyond our control is constantly upsetting to our family, we find things to do that keep our minds off our worries.	0	1	2	3	4
11.	No matter what happens in our family, we try to look "at the bright side of things".	0	1	2	3	4
12.	Even in our busy schedules, we find time to be together	0	1	2	3	4
13.	Everyone in our family understands the rules about acceptable ways to act.	0	1	2	3	4
14.	Friends and relatives are always willing to help whenever we have a problem or crisis.	0	1	2	3	4
15.	When we have a problem or concern, we are able to decisions about what to do	0	1	2	3	4
16.	We enjoy time together even if it is just doing house hold chores.	0	1	2	3	4
17.	If we have a problem or concern that seems overwhelming, we try to forget it for awhile	0	1	2	3	4
18.	Whenever we have disagreements, family members listen to "both side of the story".	0	1	2	3	4
19.	In our family, we make time to get things done that we all agree are important	0	1	2	3	4
20.	In our family, we can depend upon the support of one another whenever something goes wrong	0	1	2	3	4
21.	We generally talk about the different ways we deal with problems or concerns	0	1	2	3	4
22.	In our family, our relationships will outlast our material possessions	0	1	2	3	4
23.	Decisions like moving or changing jobs are based on what is best for all family members.	0	1	2	3	4
24.	We can depend upon one another to help out when something unexpected comes up	0	1	2	3	4
25.	In our family, we try not to take one another for granted	0	1	2	3	4
26.	We try to solve our problems first before asking others to help	0	1	2	3	4

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Family Needs Scale

Carl J. Dunst, Carolyn S. Cooper, Janet C. Weeldreyer, Kathy D. Snyder, & Joyce H. Chase

Name ______________________________ Date ____________________

This scale asks you to indicate if you have a need for any type of help or assistance in 41 different areas. Please circle the response that best describes how you feel about needing help in those areas.

To what extent do you feel the need for any of the following types of help or assistance:	Not Applicable	Almost Never	Seldom	Sometimes	Often	Almost Always
1. Having money to buy necessities and pay bills	NA	1	2	3	4	5
2. Budgeting money	NA	1	2	3	4	5
3. Paying for special needs of my child	NA	1	2	3	4	5
4. Saving money for the future	NA	1	2	3	4	5
5. Having clean water to drink	NA	1	2	3	4	5
6. Having food for two meals for my family	NA	1	2	3	4	5
7. Having time to cook healthy meals for my family	NA	1	2	3	4	5
8. Feeding my child	NA	1	2	3	4	5
9. Getting a place to live	NA	1	2	3	4	5
10. Having plumbing, lighting, heat	NA	1	2	3	4	5
11. Getting furniture, clothes, toys	NA	1	2	3	4	5
12. Completing chores, repairs, home improvements	NA	1	2	3	4	5
13. Adapting my house for my child	NA	1	2	3	4	5
14. Getting a job	NA	1	2	3	4	5
15. Having a satisfying job	NA	1	2	3	4	5
16. Planning for future job of my child	NA	1	2	3	4	5
17. Getting where I need to go	NA	1	2	3	4	5
18. Getting in touch with people I need to talk to	NA	1	2	3	4	5
19. Transporting my child	NA	1	2	3	4	5
20. Having special travel equipment for my child	NA	1	2	3	4	5
21. Finding someone to talk to about my child	NA	1	2	3	4	5
22. Having someone to talk to	NA	1	2	3	4	5
23. Having medical and dental care for my family	NA	1	2	3	4	5
24. Having time to take care of myself	NA	1	2	3	4	5
25. Having emergency health care	NA	1	2	3	4	5
26. Finding special dental and medical care for my child	NA	1	2	3	4	5
27. Planning for future health needs	NA	1	2	3	4	5
28. Managing the daily needs of my child at home	NA	1	2	3	4	5
29. Caring for my child during work hours	NA	1	2	3	4	5
30. Having emergency child care	NA	1	2	3	4	5
31. Getting respite care for my child	NA	1	2	3	4	5
32. Finding care for my child in the future	NA	1	2	3	4	5
33. Finding a school placement for my child	NA	1	2	3	4	5
34. Getting equipment or therapy for my child	NA	1	2	3	4	5
35. Having time to take my child to appointments	NA	1	2	3	4	5
36. Exploring future educational options for my child	NA	1	2	3	4	5
37. Expanding my education, skills, and interests	NA	1	2	3	4	5
38. Doing things that I enjoy	NA	1	2	3	4	5
39. Doing things with my family	NA	1	2	3	4	5
40. Participation in parent groups or clubs	NA	1	2	3	4	5
41. Traveling/vacationing with my child	NA	1	2	3	4	5

Source: C.J. Dunst, C.M. Trivette, and A.G. Deal (1988). *Enabling and empowering families: Principles and guidelines for practice.* Cambridge, MA: Brookline Books. May be reproduced.

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Family Resource Scale

Hope E. Leet & Carl J. Dunst

Name ______________________________ Date ______________

This scale is designed to assess whether or not you and your family have adequate resources (time, money, energy, and so on) to meet the needs of the family as a whole as well as the needs of individual family members.

For each item, please *circle* the response that best describes how well the need is met on a *consistent* basis in your family (that is, month in and month out).

To what extent are the following resources adequate for your family:	Does Not Apply	Not at All Adequate	Seldom Adequate	Sometimes Adequate	Usually Adequate	Almost Always Adequate
1. Food for 2 meals a day	NA	1	2	3	4	5
2. House or apartment	NA	1	2	3	4	5
3. Money to buy necessities	NA	1	2	3	4	5
4. Enough clothes for your family	NA	1	2	3	4	5
5. Heat for your house or apartment	NA	1	2	3	4	5
6. Indoor plumbing/water	NA	1	2	3	4	5
7. Money to pay monthly bills	NA	1	2	3	4	5
8. Good job for yourself or spouse/partner	NA	1	2	3	4	5
9. Medical care for your family	NA	1	2	3	4	5
10. Public assistance (SSI, AFDC, Medicaid, etc.)	NA	1	2	3	4	5
11. Dependable transportation (own car or provided by others)	NA	1	2	3	4	5
12. Time to get enough sleep/rest	NA	1	2	3	4	5
13. Furniture for your home or apartment	NA	1	2	3	4	5
14. Time to be by yourself	NA	1	2	3	4	5
15. Time for family to be together	NA	1	2	3	4	5
16. Time to be with your child(ren)	NA	1	2	3	4	5
17. Time to be with spouse or partner	NA	1	2	3	4	5
18. Time to be with close friend(s)	NA	1	2	3	4	5
19. Telephone or access to a phone	NA	1	2	3	4	5
20. Baby sitting for your child(ren)	NA	1	2	3	4	5
21. Child care/day care for your child(ren)	NA	1	2	3	4	5
22. Money to buy special equipment/supplies for child(ren)	NA	1	2	3	4	5
23. Dental care for your family	NA	1	2	3	4	5
24. Someone to talk to	NA	1	2	3	4	5
25. Time to socialize	NA	1	2	3	4	5
26. Time to keep in shape and look nice	NA	1	2	3	4	5
27. Toys for your child(ren)	NA	1	2	3	4	5
28. Money to buy things for yourself	NA	1	2	3	4	5
29. Money for family entertainment	NA	1	2	3	4	5
30. Money to save	NA	1	2	3	4	5
31. Time and money for travel/vacation	NA	1	2	3	4	5

Source: C.J. Dunst, C.M. Trivette, and A.G. Deal (1988). *Enabling and empowering families: Principles and guidelines for practice.* Cambridge, MA: Brookline Books. May be reproduced.

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Family Support Scale

Carl J. Dunst, Vicki Jenkins, & Carol M. Trivette

Name ______________________________ Date ______________

Listed below are people and groups that oftentimes are helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to ***your family***.

Please *circle* the response that best describes how helpful the sources have been to your family during the past ***3 to 6 months***. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response.

How helpful has each of the following been to you in terms of raising your child(ren):	Not Available	Not at All Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
1. My parents	NA	1	2	3	4	5
2. My spouse or partner's parents	NA	1	2	3	4	5
3. My relatives/kin	NA	1	2	3	4	5
4. My spouse or partner's relatives/kin	NA	1	2	3	4	5
5. Spouse or partner	NA	1	2	3	4	5
6. My friends	NA	1	2	3	4	5
7. My spouse or partner's friends	NA	1	2	3	4	5
8. My own children	NA	1	2	3	4	5
9. Other parents	NA	1	2	3	4	5
10. Co-workers	NA	1	2	3	4	5
11. Parent groups	NA	1	2	3	4	5
12. Social groups/clubs	NA	1	2	3	4	5
13. Church members/minister	NA	1	2	3	4	5
14. My family or child's physician	NA	1	2	3	4	5
15. Early childhood intervention program	NA	1	2	3	4	5
16. School/day-care center	NA	1	2	3	4	5
17. Professional helpers (social workers, therapists, teachers, etc.)	NA	1	2	3	4	5
18. Professional agencies (public health, social services, mental health, etc.)	NA	1	2	3	4	5
19. ______________________	NA	1	2	3	4	5
20. ______________________	NA	1	2	3	4	5

Source: C.J. Dunst, C.M. Trivette, and A.G. Deal (1988). *Enabling and empowering families: Principles and guidelines for practice.* Cambridge, MA: Brookline Books. May be reproduced.

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Personal Network Matrix
(Version 2)
Carol M. Trivette & Carl J. Dunst

Name ______________________________ Date ______________

Whenever a person needs help or assistance, he or she generally can depend upon certain persons or groups more than others. Listed below are different individuals, groups, and agencies that you might ask for help or assistance. For each source listed, please indicate to what extent you could depend upon each person or group if you needed any type of help.

To what extend can you depend on any of the following for help or assistance when you need it:	Not at All	Sometimes	Occasionally	Most of the Time	All of the Time
1. Spouse or Partner	1	2	3	4	5
2. My Children	1	2	3	4	5
3. My Parents	1	2	3	4	5
4. Spouse or Partner's Parents	1	2	3	4	5
5. My Sister/Brother	1	2	3	4	5
6. My Spouse or Partner's Sister/Brother	1	2	3	4	5
7. Other Relatives	1	2	3	4	5
8. Friends	1	2	3	4	5
9. Neighbors	1	2	3	4	5
10. Church Members	1	2	3	4	5
11. Minister, Priest, or Rabbi	1	2	3	4	5
12. Co-workers	1	2	3	4	5
13. Baby Sitter	1	2	3	4	5
14. Day Care or School	1	2	3	4	5
15. Private Therapist for Child	1	2	3	4	5
16. Child/Family Doctors	1	2	3	4	5
17. Early Childhood Intervention Program	1	2	3	4	5
18. Hospital/Special Clinics	1	2	3	4	5
19. Health Department	1	2	3	4	5
20. Social Service Department	1	2	3	4	5
21. Other Agencies	1	2	3	4	5
22. ______________	1	2	3	4	5
23. ______________	1	2	3	4	5

Source: C.J. Dunst, C.M. Trivette, and A.G. Deal (1988). *Enabling and empowering families: Principles and guidelines for practice.* Cambridge, MA: Brookline Books. May be reproduced.

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Inventory of Social Support

Carol M. Trivette & Carl J. Dunst

Name ______________________________ Date ________________

This questionnaire asks about people and groups that may provide you help and assistance. The scale is divided into two parts. Please read the instructions that go with each part before completing each section of the questionnaire.

Listed below are different individuals and groups that people often have contact with face to face, in a group, or by telephone. For each source listed, please indicate how often you have been in contact with each person or group during the *past month*. Please indicate any person or group with whom you have had contact not included on the list.

How frequently have you had contact with each of the following during the *past month*:	Not at All	Once or Twice	At Least 10 Times	At least 20 Times	Almost Every-Day
1. Spouse or Partner	1	2	3	4	5
2. My Children	1	2	3	4	5
3. My Parents	1	2	3	4	5
4. Spouse or Partner's Parents	1	2	3	4	5
5. My Sister/Brother	1	2	3	4	5
6. My Spouse or Partner's Sister/Brother	1	2	3	4	5
7. Other Relatives	1	2	3	4	5
8. Friends	1	2	3	4	5
9. Neighbors	1	2	3	4	5
10. Church Members/Minister	1	2	3	4	5
11. Co-workers	1	2	3	4	5
12. Baby Sitter, Day Care, or School	1	2	3	4	5
13. Private Therapist for Child	1	2	3	4	5
14. Child/Family Doctors	1	2	3	4	5
15. Early Childhood Intervention Program	1	2	3	4	5
16. Health Department	1	2	3	4	5
17. Social Service Department	1	2	3	4	5
18. Other Agencies	1	2	3	4	5
19. ____________________	1	2	3	4	5
20. ____________________	1	2	3	4	5

Source: C.J. Dunst, C.M. Trivette, and A.G. Deal (1988). *Enabling and empowering families: Principles and guidelines for practice*. Cambridge, MA: Brookline Books. May be reproduced.

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Support Functions Scale

Carol M. Trivette & Carl J. Dunst

Name ______________________________ Date ______________

Listed below are 20 different types of assistance which people sometimes find helpful. This questionnaire asks you to indicate how much you need help in these areas.

Please *circle* the response that best describes your needs. Please answer all the questions.

To what extent do you have or feel a need for any of the following types of help or assistance:	Never	Once in a While	Sometimes	Often	Quite Often
1. Someone to talk to about things that worry you	1	2	3	4	5
2. Someone to provide money for food, clothes, and other things	1	2	3	4	5
3. Someone to care for your child on a regular basis	1	2	3	4	5
4. Someone to talk to about problems with raising your child	1	2	3	4	5
5. Someone to help you get services for your child	1	2	3	4	5
6. Someone to encourage you when you are down	1	2	3	4	5
7. Someone to fix things around the house	1	2	3	4	5
8. Someone to talk to who has had similar experiences	1	2	3	4	5
9. Someone to do things with your child	1	2	3	4	5
10. Someone whom you can depend on	1	2	3	4	5
11. Someone to hassle with agencies or businesses when you can't	1	2	3	4	5
12. Someone to lend you money	1	2	3	4	5
13. Someone who accepts your child regardless of how (s)he acts	1	2	3	4	5
14. Someone to relax or joke with	1	2	3	4	5
15. Someone to help with household chores	1	2	3	4	5
16. Someone who keeps you going when things seem hard	1	2	3	4	5
17. Someone to care for your child in emergencies or when you must go out	1	2	3	4	5
18. Someone to talk to you when you need advice	1	2	3	4	5
19. Someone to provide you or your child transportation	1	2	3	4	5
20. Someone who tells you about services for your child or family	1	2	3	4	5

Source: C.J. Dunst, C.M. Trivette, and A.G. Deal (1988). *Enabling and empowering families: Principles and guidelines for practice.* Cambridge, MA: Brookline Books. May be reproduced.

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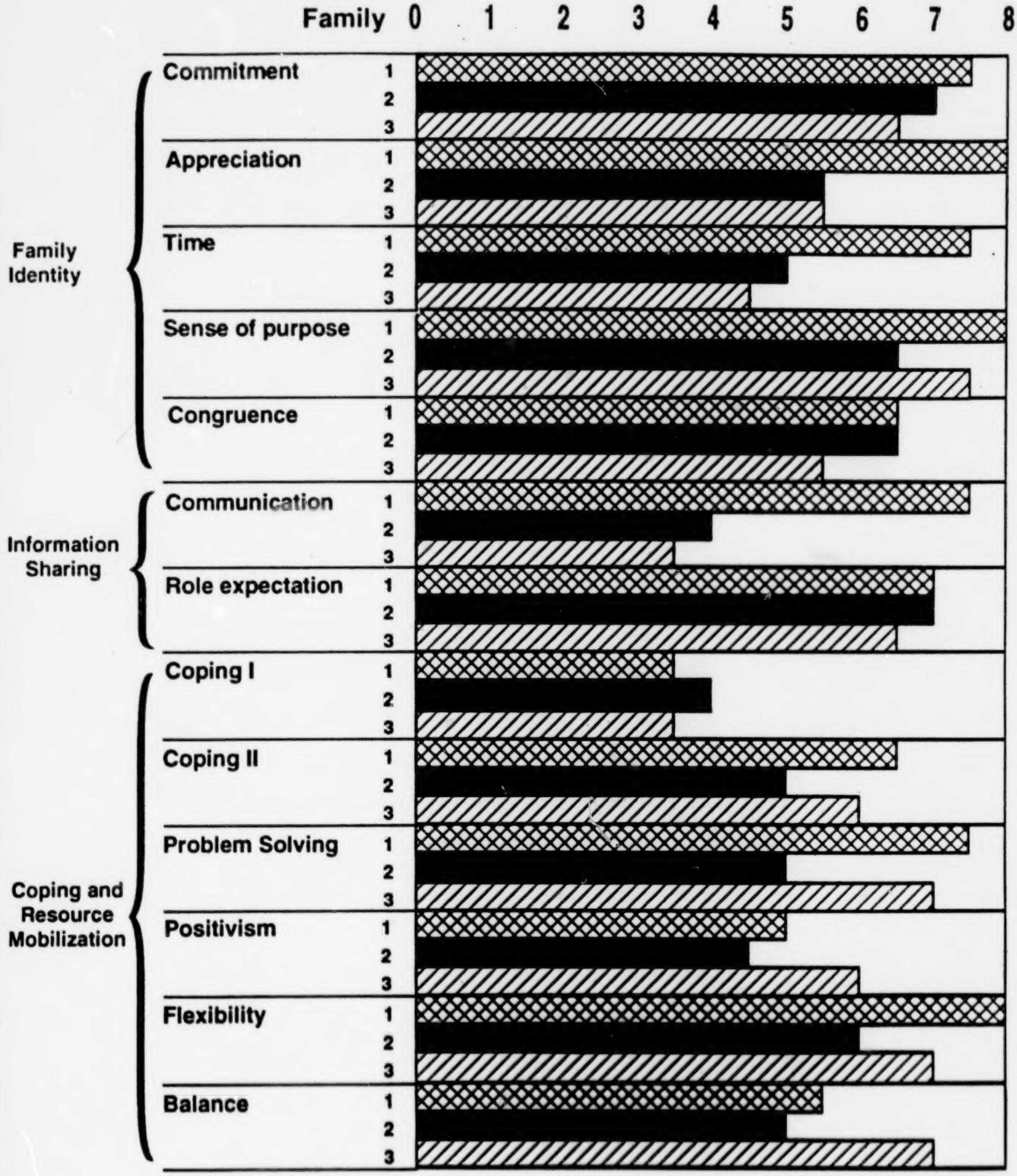
APPENDIX D

Graph

Family Profiles
Family Functioning Style Scale



APPENDIX E

Tables

Table 1
Questionnaire Data
Family Functioning Style Scale

Question: To what extent is each statement like your family?

4 = almost always
3 = generally
2 = sometimes
1 = a little
0 = not at all
x = no response

Item	Family #1 responses		Family #2 responses		Family #3 responses	
	Mo	Fa	Mo	Fa	Mo	Fa
1	3	4	3	3	3	2
2	3	4	4	3	3	4
3	2	3	2	2	2	4
4	4	4	4	3	3	3
5	3	4	3	1	2	2
6	4	4	4	3	3	4
7	1	2	2	2	4	2
8	3	4	4	3	2	3
9	4	4	3	2	2	4
10	2	1	2	1	2	2
11	3	2	3	2	2	4
12	3	4	3	2	2	3
13	3	4	4	3	3	3
14	2	3	2	2	2	3
15	4	4	3	2	4	4
16	4	4	3	2	1	3
17	2	2	3	2	1	2
18	4	4	2	2	1	2
19	3	3	3	3	3	3
20	4	4	3	3	3	4
21	3	4	3	2	2	4
22	4	4	3	3	4	4
23	4	4	4	4	4	4
24	4	4	3	4	4	4
25	4	4	2	2	2	3
26	4	4	3	3	4	4

Table 2
Questionnaire Data
Family Needs Scale

Question: To what extent do you feel the need for any of the following types of help or assistance?

5 = almost always
4 = often
3 = sometimes
2 = seldom
1 = almost never
NA = not applicable
X = no response

Item	Family #1 responses		Family #2 responses		Family #3 responses	
	Mo	Fa	Mo	Fa	Mo	Fa
1	2	NA	3	2	5	2
2	1	NA	2	3	3	1
3	3	3	3	3	5	4
4	4	NA	4	4	5	1
5	NA	NA	NA	NA	NA	NA
6	NA	NA	1	NA	1	NA
7	3	NA	1	NA	3	NA
8	NA	NA	NA	NA	NA	X
9	NA	NA	NA	NA	NA	NA
10	NA	NA	NA	NA	3	NA
11	1	NA	NA	NA	3	NA
12	3	NA	2	NA	5	1
13	3	1	NA	NA	3	1
14	NA	NA	3	NA	NA	1
15	NA	NA	3	NA	1	1
16	5	NA	3	2	NA	NA
17	2	NA	NA	2	3	NA
18	1	NA	2	2	X	NA
19	1	3	3	2	3	1
20	1	NA	NA	2	1	NA
21	4	NA	4	2	5	1
22	NA	NA	2	2	1	1
23	3	NA	NA	NA	1	1
24	3	NA	3	NA	3	NA
25	4	NA	NA	NA	2	X
26	4	NA	3	NA	5	NA
27	2	NA	1	NA	4	X
28	3	NA	3	2	3	X
29	5	5	4	1	5	X
30	4	3	4	1	5	X

Table 2 Continued

31	3	3	4	3	5	X
32	1	NA	4	1	5	X
33	5	3	NA	NA	3	X
34	3	3	1	2	5	4
35	5	2	3	1	5	1
36	4	2	4	1	5	X
37	1	NA	3	3	4	X
38	3	NA	3	3	3	X
39	2	NA	3	3	5	X
40	3	NA	3	2	4	X
41	3	NA	4	3	5	X

Table 3
Family Resource Scale
Questionnaire Data

Question: To what extent are the following resources adequate for your family?

5 = almost always
4 = usually
3 = sometimes
2 = seldom

1 = not at all
NA = not applicable
X = no response

Item	Family #1 responses		Family #2 responses		Family #3 responses	
	Mo	Fa	Mo	Fa	Mo	Fa
1	NA	NA	5	5	4	5
2	NA	NA	5	5	4	5
3	NA	NA	4	5	3	5
4	NA	NA	4	4	3	5
5	NA	NA	4	5	4	5
6	NA	NA	5	5	5	5
7	5	NA	4	5	3	4
8	5	NA	3	4	4	5
9	4	NA	4	5	5	5
10	5	NA	5	NA	3	X
11	NA	NA	4	5	3	5
12	3	NA	4	4	4	5
13	NA	NA	5	4	4	5
14	3	NA	4	4	3	4
15	4	NA	3	4	2	4
16	4	NA	4	4	2	4
17	4	NA	4	4	2	4
18	3	4	3	4	2	3
19	NA	NA	5	5	5	5
20	4	4	3	3	3	5
21	4	5	NA	4	2	5
22	4	5	NA	4	1	4
23	5	NA	5	5	3	NA
24	4	5	4	4	4	4
25	3	4	4	3	3	4
26	3	NA	4	4	2	4
27	5	NA	4	4	4	5
28	4	NA	3	3	1	4
29	4	NA	3	4	1	4
30	3	4	2	3	1	1
31	3	4	3	3	1	1

Table 4
Questionnaire Data
Family Support Scale

Question: How helpful has each of the following been to you in terms of raising your child(ren)?

5 = extremely helpful
4 = very helpful
3 = generally helpful
2 = sometimes helpful
1 = not at all helpful
NA = not available
X = no response

Item	Family #1 responses		Family #2 responses		Family #3 responses	
	Mo	Fa	Mo	Fa	Mo	Fa
1	3	1	1	4	3	4
2	1	3	1	4	3	4
3	NA	NA	1	2	2	2
4	1	NA	1	2	2	2
5	5	5	4	5	4	5
6	2	2	2	4	2	1
7	1	2	NA	4	1	1
8	NA	NA	3	4	2	3
9	2	NA	2	2	2	1
10	2	NA	NA	2	2	2
11	2	1	1	2	2	NA
12	NA	1	1	2	X	NA
13	NA	NA	1	2	2	X
14	4/5	5	4	4	4	X
15	NA	NA	5	3	4	X
16	1	2	5	3	4	4
17	3	2	2	3	4	4
18	2	NA	2	3	3	X
19	1	X	X	X	X	X
20	X	X	X	X	X	X

Table 5
Questionnaire Data
Personal Network Matrix (part A)

Question: How frequently have you had contact with each of the following during the past month?

5 = almost every day
4 = at least 20 times
3 = at least 10 times
2 = once or twice
1 = not at all
X = no response
NA = not applicable

	Family #1 responses		Family #2 responses		Family #3 responses	
Item	Mo	Fa	Mo	Fa	Mo	Fa
1	5	5	5	5	5	5
2	5	5	5	5	5	5
3	3	2	1	3	3	2
4	2	3	2	1	2	2
5	1	2	2	2	3	2
6	2	2	2	2	2	2
7	2	2	2	2	2	2
8	3	3	4	2	4	5
9	2	2	4	3	2	2
10	NA	1	2	2	3	1
11	NA	1	3	2	2	1
12	5	1	1	4	5	2
13	4	3	1	1	2	3
14	3	3	2	2	5	4
15	2	1	1	1	1	4
16	2	1	2	1	2	2
17	NA	1	1	1	2	X
18	1	1	3	1	1	X
19	1	1	X	1	1	1
20	3	2	2	1	2	1
21	2	1	2	1	3	1
22	2	X	X	X	3	X
23	3	X	X	X	2	X

Table 6
Questionnaire Data
Personal Network Matrix (part C)

Question: To what extent can you depend on any of the following for help or assistance when you need it?

5 = all of the time
4 = most of the time
3 = occasionally
2 = sometimes
1 = not at all
X = no response
NA = not applicable

	Family #1		Family #2		Family #3	
	responses		responses		responses	
Item	Mo	Fa	Mo	Fa	Mo	Fa
1	4	5	4	4	4	5
2	1	1	4	3	4	3
3	2	X	3	4	3	4
4	1	X	3	4	3	4
5	2	X	2	4	3	2
6	1	X	2	3	2	2
7	1	X	1	2	1	2
8	3	X	2	4	3	2
9	1	X	2	3	2	2
10	NA	1	1	3	2	2
11	NA	1	2	3	2	1
12	2	1	2	2	2	2
13	4	4	3	2	4	3
14	1	3	4	2	4	3
15	2	1	1	2	3	3
16	4	5	3	2	4	X
17	NA	1	1	2	3	X
18	3	5	2	2	3	X
19	NA	3	2	2	2	X
20	3	4	2	2	3	X
21	2	1	X	2	2	X
22	1	X	X	X	X	X
23	X	X	X	X	X	X

Table 7
Questionnaire Data
Inventory of Social Support

Question: How frequently have you had contact with each of the following during to past month?

5 = almost every day
4 = at least 20 times
3 = at least 10 times
2 = once or twice
1 = not at all
X = no response
NA = not applicable

	Family #1 responses		Family #2 responses		Family #3 responses	
Item	Mo	Fa	Mo	Fa	Mo	Fa
1	5	5	5	5	5	5
2	5	5	5	5	5	5
3	3	2	2	3	3	2
4	2	3	2	2	2	2
5	1	2	2	2	3	2
6	2	2	1	2	2	2
7	2	2	1	2	2	2
8	3	3	3	2	4	5
9	2	2	3	2	2	2
10	NA	1	2	3	2	1
11	5	5	1	4	5	2
12	4	5	4	1	4	4
13	2	1	1	1	2	4
14	2	1	3	1	2	2
15	NA	1	1	1	2	X
16	1	1	1	1	1	X
17	3	2	2	1	2	X
18	2	1	X	1	2	X
19	2	X	X	X	3	X
20	3	X	X	X	2	X

Table 8
Questionnaire Data
Support Functions Scale

Question: To what extent do you have or feel a need for any of the following types of helps or assistance?

5 = quite often
4 = often
3 = sometimes
2 = once in a while
1 = never
X = no response
NA = not applicable

	Family #1 responses		Family #2 responses		Family #3 responses	
Items	Mo	Fa	Mo	Fa	Mo	Fa
1	3	2	3	2	3	2
2	1	1	1	2	5	1
3	5	5	3	3	4	2
4	4	2	3	3	4	1
5	3	2	4	3	3	2
6	3	2	3	2	3	2
7	3	1	1	2	4	2
8	3	1	4	2	5	2
9	3	4	3	2	4	2
10	2	5	1	2	3	2
11	3	2	3	2	4	2
12	2	2	2	2	4	2
13	3	5	4	3	4	3
14	1	5	3	3	3	3
15	3	X	2	2	3	3
16	2	X	3	2	3	2
17	2	2	4	3	3	2
18	2	X	3	3	3	2
19	1	X	3	2	3	2
20	2	X	4	2	3	2

APPENDIX F

Maps Questions

THE MAPS ACTION PLANNING SYSTEM (Forest and Lusthaus, 1990)

Maps is a planning process used to facilitate full participation of disabled children (and adults) into culturally normative community-based activities. After a brief period to welcome all participants and to help everyone feel comfortable, the planning session begins. It consists of discussions of the following questions:

- What is ----------------'s history?
- What is your dream for ----------?
- What is your nightmare -----------?
- Who is --------------?
- What are ------------'s strengths, gifts, and talents?
- What are ------------'s needs?
- (What would be an ideal day for ------?

Responses are recorded for later use.